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Dawn Reeves (BSc Hons)

INVESTIGATION INTO THE PSYCHOLOGICAL
FACTORS ASSOCIATED WITH
ADJUSTMENT IN PEOPLE WITH LEG AMPUTATION

A thesis submitted in partial fulfilment of the requirements of the Open University for
the degree of Doctor of Clinical Psychology.

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Abstract

Adjustment difficulties can be a common problem for people with acquired physical disability. Depression can often be a sign that a person is having difficulties adjusting to and accepting change. One group of people with acquired disability are those who have had a limb amputated due to trauma, cancer, vascular disease or a congenital condition. People who have had an amputation are more likely develop depression than the general population. This study is an investigation into some of the factors (coping strategies, mood, and personality variables) associated with adjustment to amputation. Forty individuals with amputations were asked to complete a set of questionnaires and participate in a short taped interview. Coping strategies were measured using the COPE and personality variables were measured using the Structural Profile Inventory (SPI). Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HAD). Life satisfaction was measured using the Life Satisfaction Index (A) (LSI). The HAD and LSI were used as indicators of possible adjustment difficulties. Short interviews were also conducted to find out about people's perception of the care that they had received and if these were related to coping strategies. Statistical analysis showed that two coping strategies, positive reinterpretation and growth, and humour, were both associated with higher levels of life satisfaction. Mental disengagement was associated with lower levels of life satisfaction. Personality variables were associated with coping strategies. Two personality variables (Behaviour and Affect) were related to life satisfaction and anxiety. Qualitative analysis of interviews showed that people valued the support of other amputees and wanted services to provide more access to information about the range of artificial limbs available to them. The findings supported the hypothesis that personality is related to the use of particular coping strategies. This could help inform clinical practice, psychological intervention, and physical rehabilitation programmes.

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1. INTRODUCTION

1.1 Perceptions of Physical Disability

Adjustment to acquired physical disability is a very individual process. Some people adjust to the loss and change more easily than others. This study aims to identify some of the factors that account for the differences between people when they are adjusting to acquired physical disability. Of particular interest is the usefulness of the concepts from multimodal theory (Lazarus, 1992) when applied to psychological adjustment to physical disability.

Research has shown that people with acquired physical disabilities are more likely to develop depression or experience adjustment disorders than the general population (McColl & Skinner, 1992). For people who do experience psychological distress the crucial element underlying adjustment difficulties is their perception of the disability, more than the actual extent of physical limitations (Eberhardt, Larsson, & Nived, 1993).

A number of factors can affect a person's subjective perception of acquired physical disability. Factors found to be associated with negative perceptions of disability and psychological difficulties include altered body image, social isolation, social discomfort, and stigma (Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995) and negative fixation on diagnosis and the cause of disability (Viemer & Krause, 1998). In contrast, physically disabled people who are considered to be well adjusted have been found to be engaged in more meaningful activities (such as work or hobbies), achieve greater social integration and are able to recognise some positive aspects of their disability (ibid.).

A sense of powerlessness is reported to be a common feeling experienced by people with a physical disability (Davidhizar, 1997). Feelings of powerlessness can develop when a person adheres to treatment regimens, takes their medication, attends physical therapy and exercises regularly, but does not notice any obvious signs of improvement (Drew, 1990). Staff need to be aware of the consequences of feelings of helplessness and powerlessness because it can have a negative effect on a person's motivation and ability to adapt to disability. For some patients, staff might have to reconsider how they approach their rehabilitation and care so that their feelings do not get worse (Conwill, 1993).

Adaptation to a disability is a process that involves "assessing, coping with and gradually assimilating various changes in body, self, and ... environment interactions necessitated by the disability" (Livneh and Antonak, 1991, p. 299). Therefore, holistic physical rehabilitation programmes that consider both the physical and psychological adjustment issues involved in acquired disability are likely to be more helpful to patients, than programmes which are mainly focused on functional adaptation.

Patients will probably find it harder to achieve functional independence if, for example, they are having difficulty coming to terms with their situation emotionally. Physical abilities that were once taken for granted can no longer be relied upon or are just not possible and the person has to relearn or change the way they interact with the world and their immediate environment. This requires a lot of effort, will power, determination and courage. It is not easy having to relearn how to walk, bathe, eat or do a number of different activities that were once so easy and automatic. One group of patients who experience intensive rehabilitation in the weeks following surgery are people who have had an amputation.

1.2 Amputation

There are three main reasons for amputation - vascular disease, benign or malignant tumours and traumatic injuries (Fitzpatrick, 1999). In the financial year from April 1997 - March 1998 there were 5896 new referrals to prosthetic service centres across the U.K (Information & Statistics Division the National Health Service in Scotland, 1999). The most common causes of amputation given during this period was trauma (e.g. road traffic accident) and vascular disease (e.g. diabetes). Of all the referrals made, sixty-five percent were male and the median age was 68 years. The most common type of amputation reported was below the knee (46%). As a percentage of all referrals, ninety-five percent were lower limb amputations (ibid.).

Psychological reactions after amputation have been likened to grief and bereavement (Parkes, 1975). It is highly likely that the person will experience some mourning for the loss of a limb, its associated function, and possible losses to lifestyle and body image (Carpenito, 1991). A review of the literature on psychological reactions to amputation shows that while the medical model prefers to talk of stages to adjustment (Butler, Turkal, and Seidl, 1992), the psychological model is more focused on the processes and phases involved in adjustment. Fitzpatrick (1999) criticises the medical model for being too prescriptive. He states that “the process of acceptance is not accomplished once and for all, nor does it march through fixed stages to ultimate acceptance” (Fitzpatrick, 1999, p.102), but rather, “recovery is a process and stress points occur as time passes influenced by developmental issues and by other life events” (ibid., 1999, p.103). Adaptation to the loss of a limb(s) is a life long process and long term amputees can be just as vulnerable to periods of distress as newer amputees (Rybarczyk, et al., 1995). However, there does appear to be general agreement amongst writers that

psychological reactions to amputation can include phases of denial, anxiety, depression, and reorganisation (Butler et. al, 1992; Livneh, Antonak, & Gerhardt, 1999).

1.2.1 Depression and adjustment difficulties following amputation

Research has shown that people with amputations are at high risk for developing depression and other psychological problems (Williamson, Schulz, Bridges, & Behan, 1994). Some estimates suggest that the rate of clinical depression in amputees is between twenty-one and thirty-five percent (Rybarczyk, Nicholas, & Nyenhuis, 1997; Kishani, Frank & Kashani, 1983). This compares with estimates of depression in the general population that range from fifteen to twenty percent (Fennell, 1996).

Depression following amputation has been studied with particular interest in demographic variables as significant factors in adaptation. Some studies have found that depression and adjustment difficulties in amputees is associated with the type of amputation (Williamson et al, 1994), age of patient (Dunn, 1996; Livneh et al, 1999), reason for amputation (Ham and Cotton, 1991), and time since amputation (Rybarczyk et al, 1995; Livneh et al, 1999). However, other studies have not found a relationship between adjustment difficulties and age or reason for amputation (Rybarczyk, Nyenhuis, Nicholas, Schulz, Alioto and Blair, 1992; Rybarczyk et al, 1995). Rybarczyk et al (1997) criticise findings that suggest a relationship between reason for amputation and depression. They argue that such studies do not take into account the possibility that the depression predated the amputation and was due more to the particular chronic condition which caused the operation (ibid.).

1.2.2 The effect of subjectivity on perceptions of disability and adjustment

Some researchers (Rybarczyk et al, 1997 and Williamson et al, 1994) have become more interested in subjective factors associated with depression and how they are related to adjustment to amputation. For instance, Rybarczyk et al (1997) argue that in the case of the type of amputation “the degree of impairment, irrespective of other factors, is too simplistic to serve as an important predictor of an individual’s overall adjustment” (p.243) and that “personality and coping strategies that may contribute to positive adjustment have yet to be examined” (p.252). So, psychological factors would probably be better at predicting levels of distress than physical factors.

Williamson et al (1994) believe that a major issue in adjustment is an individual’s perception of their own level of functional independence (i.e. level of disability). They surveyed 160 amputees and found that three distinct factors accounted for forty percent of the variance in depressive symptomatology. These factors were younger age, less satisfaction with social contacts and the perception that their activities were restricted because of the amputation. Pell, Donnan, Fowkes and Ruckley (1993) found that amputees were more likely to report feelings of isolation than a control group, even though both groups included equal numbers of participants living on their own. Rybarczyk, et al, (1995) found that forty percent of the variance in depression scale scores of amputees was related to responses on measures of body image, perceived social stigma and perceived social support. This is despite the fact that most amputees are not easily recognisable. For example, when clothed their prosthesis would not appear any different from a real leg (Racy, 1989).

These studies highlight the role of subjective evaluation in psychological adjustment to amputation. Williamson et al (1994) and Pell et al's (1993) participants both demonstrated how personal and individual subjective interpretation and evaluation of the level of social contact and functional limitation affected mood. Those who judged themselves to be more isolated and restricted were more likely to feel depressed. Rybaarczyk et al (1997) point out that objective measures of physical impairment are actually relatively poor predictors of mental health. Rather, it is the individual's own personal perception of impairment that is more predictive of distress. It suggests that rehabilitation staff should listen to the person's own subjective assessment of their disability. Staff should consider how rehabilitation is affected when there is a big gap between objective and subjective measures of disability, especially as this could be a signal that the person is quite distressed.

As Fitzpatrick (1999) states, "disability after amputation is often far more the result of individual and social attitudes than it is with the loss of the limb. It is the loss of the ability to relate psychologically, vocationally, avocationally, sexually and socially that inhibits the most (p.100). Biased social attitudes can stem from the disabled person as much as from any other individual. A disabled person's expectation of negative treatment from others could lead to distorted beliefs about what other people are actually thinking or feeling (Rybarczyk et al., 1997).

One criticism of these studies (Pell et al, 1993; Williams et al, 1995; Rybarczyk et al, 1995) is that they do not look at the issue of positive perspectives and adjustment to amputation (Dunn, 1996). Dunn (1996) believes that research on adjustment to amputation should focus more on each individual persons' understanding and interpretation of events. In a study of

138 amputees she found that people with higher levels of self-esteem were more optimistic and more likely to feel that they had some control over their disability. Levels of depressive symptomatology were higher in people who had not found meaning to their experience. They were less optimistic than other amputees and felt that they had less control over events. Research evidence from other populations supports this finding. Studies have shown that a sense of control and an optimistic attitude can reduce levels of stress (Aldwin, 1996; Taylor and Aspinwall, 1996).

Dunn's (1996) research findings however are vulnerable to a number of methodological criticisms. Participants were recruited from a regional amputee golf association, the sample only included 15 women, and nearly half were educated to degree level or above. In fact, Dunn (1996) admits that her participants were quite advantaged and affluent compared to the average amputee. The reason for amputation was not evenly spread either, with a high percentage being related to trauma (67.4%). She also used untraditional ways of measuring and defining coping strategies (Livneh, et al, 1999). Positive meaning and perceived control were assessed on the basis of just one item.

Despite its obvious limitations Dunn's study does address some of the criticisms of previous research on amputation. Previous studies have provided little information about what kind of psychological processes facilitate adjustment to amputation and habituation to life with a prosthesis (Fitzpatrick, 1999). Rather they have tended to focus on proving a unidirectional relationship between disability and depression (Williams et al, 1995). Little mention has been made about the possibility that depression increases levels of disability by adversely affecting motivation and participation in activities (Rybarczyk et al, 1997). Dunn's (1996) untraditional

methods also allowed for a more qualitative analysis of amputees experiences. Some of her questions were open ended which meant that respondent's personal views were more accessible to the reader, rather than just presented in the form of statistics from forced choice questionnaires (Rybarczyk, et al, 1997).

1.2.3 Coping strategies and adjustment to amputation

Health psychology research has stimulated much debate about the role of individual meaning and interpretation of particular events in the face of ill-health. Research focusing on coping styles and strategies is particularly interesting, with a long running debate about whether it is situation or person specific variables that have the greatest impact on a person's ability to adjust and adapt to life stressors (see Lazarus, 1999, for an overview).

Lazarus (1999) believes that a person's ability to cope with stressful events is influenced by their personality and the situation they are in. There are two main approaches in the study of coping, the contextual/ process approach (e.g. Lazarus and Folkman, 1984) and the dispositional/ state-trait approach (e.g. Costa, Somerfield and McCrae, 1996).

The contextual/ process approach conceptualises coping in terms of cognitive appraisals and coping responses associated with specific situations and stressors. More specifically, coping is thought of as an effortful process that people engage with to manage psychological stress (Lazarus, 1999). Alternatively, the state-trait perspective conceptualises coping in terms of personal preferences for particular styles of coping that are stable across different situations and stressors. Personality variables are said to influence coping thoughts and behaviours (Costa et al, 1996). Unlike the process approach, this model considers coping to be an integral

part of human personality and behaviour and not an effortful process of separate functional groups of behaviour (Costa et al, 1996).

Both approaches divide coping into two different categories, emotional and cognitive behavioural. In the process approach these are considered to be the major functions of coping and are referred to as problem and emotion focused coping (Lazarus, 1999). Problem focused coping refers to when a person attempts to get more information about what to do and then takes action to change a stressful situation. Emotion focused coping is about regulating emotional reaction to a stressor by avoiding or appraising it. In the state-trait approach the two categories are called active approach or emotional avoidance coping (Holahan, Moos, & Schaefer, 1996). They are similar to problem and emotion focused categories. An active approach to coping could be where someone takes direct efforts to resolve a problem. Emotional avoidance is where a person avoids the problem and instead focuses on managing the emotions it evokes (ibid.).

Theories of coping are relevant to issues of adjustment in amputation because they provide a framework for understanding why different people respond in different ways to a similar experience. More specifically, studies that look at the different coping styles or traits of people who have had an amputation could provide further information about the pattern of variables that are associated with depressive symptomatology in this group. This kind of knowledge could help to inform rehabilitation practices and intervention programmes. As Gallagher and MacLachlan (1999) state, “the rehabilitation team must be aware of the coping strategies that patients employ and whether they are likely to be adaptive or to interfere with the patient’s recovery” (p.122).

Two recent studies (Gallagher & MacLachlan, 1999; Livneh et al, 1999). have investigated the role of coping strategies in adjustment to amputation. Gallagher and MacLachlan (1999) found that avoidance was the predominant coping strategy used by trauma related amputees. Trauma was also highly associated with stump pain, which in turn was related to higher levels of despair and social withdrawal. They also found that participants who scored low on avoidance, but high on measures of social support, reported higher levels of despair than those with low scores on both avoidance and social support. Gallagher and MacLachlan (1999) believe that this means it is better for amputees to rely on their own ability to deal with adjustment issues rather than seek support from other people. In this sample of amputees, support from others did not appear to offer any particular benefits in terms of reducing levels of despair.

This study, like many others on amputation, suffered from small sample size. It also had a low response rate with only twenty-six and a half percent of the total number of amputees invited to take part actually returning their questionnaires. Further criticisms are that only three coping strategies were measured and the gender balance of the sample was not representative of amputees as a group. The conclusion that social support is not particularly beneficial is also quite tentative especially since they did not investigate this further. Social support could have increased following an increase in depressive symptoms and may not necessarily have been a precursor to it.

A slightly larger study with 61 participants, by Livneh et al (1999) included measures for 17 coping strategies. They found that active-problem solving coping (e.g. planning, positive reinterpretation and seeking social support) was associated with lower levels of depression and

high scores on adjustment and acceptance of disability. Emotion focused coping styles (e.g. focusing on and venting emotions, self criticism, and social withdrawal) and cognitive disengagement (e.g. denial and mental disengagement) were related to higher levels of depression and hostility, and low acceptance of disability. Acceptance of disability was highest amongst older long term amputees and lowest amongst both young and old newer amputees

These findings are contrary to Gallagher and MacLachlan's (1999) findings which suggested that social support was not helpful for people with depressive symptomatology and that it was more beneficial for people to deal with adjustment issues on their own. Livneh et al (1999), found that withdrawal was more associated with depression and that social support was more associated with positive adjustment. Recruitment differences could account for the discrepancy in results. Livneh et al's (1999) participants were all recruited from an amputee support group which may have biased the findings. Obviously they found the social contact with other amputees very supportive and as a group may have scored higher on measures of adjustment and lower on indicators of depression. On the other hand, Gallagher and MacLachlan's (1999) sample were self selecting (they completed and returned their questionnaires) and were chosen from the records of a limb fitting centre. Also, they might only have had access to social support from friends and family. It could be that this kind of support is not as beneficial as support given by fellow amputees.

1.3 Coping Strategies and Personality Variables

The differences between amputees from various research studies shows how much people can vary in their response and adjustment to amputation. It suggests that adjustment is a complex

and multidimensional process. It is affected by personal perceptions about level of disability and social contact. It also seems to be influenced by styles of coping. One aspect that research on amputation has not yet investigated is the issue of personality variables. As stated above, Rybarczyk et al (1997) called for further examination of the importance of personality factors as well as coping strategies. The relationship between personality factors and coping has already been the focus of much discussion in literature on stress and coping (see Zeidner and Endler, 1996).

Costa, Somerfield and McCrae (1996) believe that coping strategies are an integral part of psychological and behavioural processes and should not be seen as separate constructs. They argue that research on coping should take into account the effect of personality traits when trying to explain the use of different coping strategies. Lazarus (1999) agrees and criticises coping measures for not assessing personality variables. He states that the lack of assessment of personality variables “deprives research on coping of the most important factor in stress, emotion and coping, which is the relational meaning an individual constructs from an adaptational transaction” (Lazarus, 1999, p. 124). By this he means that in order for someone to adapt to a stressful situation they must reappraise the situation and give new meaning to it, a meaning which will cause less emotional disturbance. An example of this would be Dunn’s (1996) participants who spoke about the gains they felt they had had since their amputation. Lazarus (1999) believes that the new meaning a person constructs will depend on “personality variables, such as goal commitments, beliefs about self and world, and personal resources” (p.124). Therefore, research into coping processes should include an assessment of the personality variables that effect how a person appraises a particular event (ibid.).

One personality variable that has received a certain amount of attention is optimism (Hewitt and Flett, 1996). As the above discussion showed, Dunn (1996) found that optimism was related to lower levels of depression in amputees. Optimism has also been shown to be related to lower levels of distress among a group of breast cancer patients (Carver, Harris, Noriega, Scheier, Robinson, Ketcham, Moffat, and Clark, 1993). Women who were more optimistic tended to use more positive coping strategies such as positive reframing and acceptance, and less negative coping styles such as denial and disengagement. There is also evidence to suggest that people who tend to have negative social expectancies (i.e. more pessimistic) are more likely to experience depressive symptoms, anxiety and use so-called negative coping strategies such as avoidance and distancing (Flett, Hewitt, and Belanger, 1993).

However, Lazarus (1999) warns that such findings should be treated with caution, especially with regards to denial. Denial can be both harmful and beneficial depending on the particular time it is used. Lazarus (1999) illustrates the point with regards to a heart attack. Denial during a heart attack is going to be harmful if it means that the person delays seeking medical help, however, it is beneficial during hospitalisation because it reduces levels of stress caused by fear of dying, but on discharge it could be harmful again because the person ignores advice to change their lifestyle. In relation to amputation, an example of denial being harmful could be prior to amputation, where someone delays seeing a doctor about poor circulation and discolouration in their leg. It might be useful around the time of the operation if it stops someone from dwelling on fears about the future and potential disability.

Costa, Somerfield and McCrae (1996) have investigated coping behaviours using McCrae's (1992) five factor model of personality. The model conceptualises personality in terms of five

psychological dimensions: neuroticism, openness to experience, agreeableness, extraversion and conscientiousness. Each trait is characterised by a set of stable patterns of thoughts, feelings and actions. The problem with this approach to coping is the way it conceptualises personality. There is an underlying notion that personality is a static concept and that people exhibit little change in coping behaviours over time or across situations. This kind of model is of little use if one wants to investigate the processes involved in adaptation to, and change in, acquired disabilities such as amputation. It is a particularly restrictive approach when one considers the limited relevance it would have in informing any kind of clinical intervention. Indeed, Costa, Somerfield and McCrae (1996) state that “personality traits are not easily altered and do not offer a ready avenue of intervention” (p.57).

If coping is associated with personality traits and these are difficult to change then coping behaviours must also be hard to change. This is not a particularly helpful notion when one considers the evidence linking depression and higher levels of distress with certain coping strategies. Surely, one of the aims for psychological intervention in such cases would be to encourage the person to use other coping strategies that have been found to be more helpful.

Therefore, a model of personality that does not lend itself easily to intervention is of little clinical use. Williamson et al (1994) suggest that if any intervention is to be successful in facilitating adjustment to amputation it must be able to “attend to the wide variety of problems faced by amputees - concerns that encompass social, psychological, financial, medical, and practical domains” (p.265). Weed and Hernandez (1990) believe that once such approach is Arnold Lazarus’ (1989) multimodal approach to therapy. It is also an approach that offers a

more clinically useful model of personality. In addition, it considers the impact that personality characteristics have on the processes of therapy and rehabilitation.

1.4 Multimodal Model of Personality Differences

Lazarus (1989) proposes that human personality can be divided into seven different but interacting modalities. These are behaviour, affect, sensation, imagery, cognition, interpersonal relationships and biological/ health processes. He believes that people differ in terms of their individual preferences and tendencies towards some modalities over others. The preferences are similar to personality traits, but they are not as rigid or inflexible as McCrae's notion of traits (1992). Lazarus also asserts that change in any of the modalities would impact on the functioning of other modalities. It is not a static conceptualisation of personality, rather a conceptualisation based on the potential for change.

According to Lazarus (1992) preferences towards certain modalities can be seen in the way that people think, feel and behave. The *behaviour* modality refers to action orientated people, so called "doers", who like to keep busy and engaged in many activities. *Affect* is about how emotional someone is. For instance, how deep they feel about things. *Sensation* refers to sensory experiences such as food, music and art, or bodily aches and pains. *Imagery* is about how much of a thinker in pictures a person is, how much they engage in vivid daydreaming and visualisation. *Cognition* refers to how much of a thinker someone is, if they like to plan and reason things. *Interpersonal* is how sociable a person is, do they place a high value on close friendships and social interaction? *Drugs /Biology* is a modality about how health conscious a person is; how much they engage in health promoting behaviours.

A characteristic of the practice of multimodal therapy is its emphasis on matching intervention practices with individual modality preferences. There is evidence to suggest that wide discrepancies between therapists and clients on modality profiles can have negative effect on outcomes (Herman, 1991). This has some relevance to rehabilitation practices for amputees. Rehabilitation is often focused on functional adaptation and the physical aspects of adjustment, while this might suit some people, it is possible that others benefit from this only when problems in other areas are addressed as well, such as the emotional adaptation to amputation. Therefore, this study will also include some qualitative information about people's perceptions of care and rehabilitation following amputation to see how or if this relates to modality preferences. There are few published accounts of people's own experience of the rehabilitation for amputation. Most of what has been written so far are autobiographical accounts.

Lazarus (1992) advocates an integrative approach to therapy which emphasises "treatments of choice" (p.237) and "tailored interventions" (p.237) whereby proven therapeutic strategies are selected on the basis of their fit with client's "goals, coping behaviours and situational contexts" (p.237). With regards to learning new and more helpful coping strategies, he asserts that "effective therapy often calls for coping skills training" (p.237). Commenting on multimodal therapy, Lazarus (1992) points out that "many clients require counsellors to select and use specific techniques to help them develop coping skills for problems identified in their modality profiles" (p.395).

1.4 Rationale

Evidence suggests that adjustment to amputation is not an easy process and can often include periods of distress. Rates of depression amongst people with amputations are higher than those reported for the general population. Research shows that elevated levels of depression in this particular group of people is not simply a reaction to acquired disability or functional limitations. Depression is not just associated with the more recent amputees, it is also seen in people who lived with amputation for several years (Rybarczyk et al, 1995). The association between amputation and depression is quite complex. It can be affected by a person's own perception of their disability, the kind of social support they have access to, and the type of coping strategies they use to deal with stressful situations.

Clearly, high levels of depression amongst people who have an amputation is an issue relevant to clinical psychology. Clinical psychologists can use a range of approaches to treat depression and often see people in therapy who are having problems adjusting to certain changes or losses in their life. There is evidence to suggest that the adjustment difficulties and depression experienced by people who have had an amputation(s) could be maintained or made worse by the kind of coping strategies (e.g. avoidance or social contact) a person typically uses to alleviate distress. For example, a review of the literature on coping and adjustment issues for people who have had an amputation suggests that strategies such as denial and certain kinds of social support can be unhelpful, whereas, strategies such as positive reinterpretation and problem solving are generally helpful.

Many approaches in clinical psychology recognise the benefits of coping strategies such as problem-solving and positive reinterpretation in treatment for depression and other

psychological disorders. In cognitive behavioural therapy (Beck, 1979) clients are taught how to actively reinterpret the kinds of cognitive distortions or negative automatic thoughts that maintain and exacerbate symptoms of depression. In systemic family therapy, there is a technique called positive reframing, where, put simply, the client's issue or problem is described in a positive way by the therapist to make it seem more open to potential solutions.

To summarise, the clinical implications of this research are twofold. Firstly, it could identify some of the common factors associated with the development of depression in people with amputation. Secondly, knowledge of these factors could help in predicting which people are at higher risk of developing depression after they have had an amputation(s). If certain factors such as particular coping strategies and personality variables (modality preferences) were found to be associated with adjustment difficulties and depression, then those patient's showing tendencies towards such thoughts or behaviours could be identified early on and offered some kind of psychological therapy to help reduce the risk of them developing depression.

The aim of this investigation then, is to study the usefulness of the concepts from multimodal theory when applied to psychological adjustment to physical disability, in this case amputation. Of particular interest is how differences in modality profiles are related to coping styles and adaptation to amputation. For example, people who are very action orientated are probably more likely to engage in active type coping behaviours as they attempt to adapt and adjust to changes or stressful events in their lives. Whereas, a person who shows strong preferences towards the Interpersonal modality might be more inclined to use coping strategies that involve social interaction and contact as a way of dealing with life's difficulties.

Previous research has not looked at amputees perceptions of the care they receive. Results from this part of the study could have interesting clinical implications and help with future service developments. This also addresses Rybarczyk et al's (1997) call for more qualitative information about the issues involved in adjusting to acquired disabilities such as amputation.

1.4 Hypotheses

1. Some sociodemographic factors such as age, gender, time since amputation, reason for amputation, and level of physical disability, will be related to different coping strategies and modalities
2. Some coping strategies will be related to levels of depression, anxiety and life satisfaction.
3. Some Modalities will be related to levels of depression, anxiety, and life satisfaction.
4. Modalities will be related to coping strategies.

2. METHODS

2.1 Design

This study is based on a cross-sectional correlational design. Five questionnaires were administered to a random group of adult amputees attending a limb fitting centre and in-patients of an amputation rehabilitation unit. Qualitative data were also collected from a short semi-structured interview. The results from questionnaires were collated and analysed using Pearson's r correlation, independent t test, and regression. Content analysis was used to analyse the data from the interviews. The resulting themes were compared with the results from the quantitative measures.

2.2 Participant Selection

Forty amputees participated in this study. Twenty-nine men and eleven women. Their ages ranged from 25 - 91 years old (mean = 58.57, SD = 17.08). The type of amputation included above and below knee, bilateral and unilateral. Reasons for amputation included motorcycle accident, cancer, and diabetes. The time since amputation ranged from 0 - 60 years (mean = 18.67, SD = 20.44).

Participants were recruited at a limb fitting centre and an in-patient rehabilitation unit for recent amputees. Amputees attending appointments (on the days the researcher was visiting) were asked by their prosthetist if they would be interested in taking part in a research project. The days on which recruitment took place varied and patients of all ages, sex, type of amputation, reason for amputation, and time since amputation were approached. In the in-patient unit patients were approached by the researcher at random. These were a group of

recent amputees and included men and women of all ages, type of amputation and reason for amputation.

2.3 Measures

Five questionnaires were used in this study: The Functional Limitations Questionnaire (shortened version), The Structural Profile Inventory (SPI), the COPE, The Hospital Anxiety and Depression Scale (HAD), and The Life Satisfaction Index (LSI-A) (see appendices 1-5). The measures were largely chosen because of their brevity and understandability, and for reasons of comparison and reliability. The researcher did not want to overwhelm volunteers with a battery of questionnaires that would have taken a long time to complete and could have deterred them from taking part. All of the measures, except for the SPI, are relatively well used and established in clinical and research settings. This meant that the findings would be well situated and more easily comparable with previous studies.

The Functional Limitations Questionnaire (FLP), (Charlton, Patrick and Peach, 1983)

The Functional Limitations Questionnaire was chosen because it includes a variety of statements that cover a wide spectrum of mild to severe physical difficulties, and so provided adequate discrimination between respondents. Sections on physical mobility from other questionnaires such as the Nottingham Health Profile (Hunt, 1984), were not suitable because they did not measure mild symptoms of physical disability. Respondents with mild to moderate symptoms would have been grouped together despite having very different levels of disability.

The present study used a shortened version of the FLP. Only the categories that make up the physical dimension were used. These are ambulation, body care and movement, mobility and household management. Together these categories make up 55 items. Each item consists of a statement about restriction of activity. Respondents are required to tick those items that described them “today” and are related to their health. Scores for each item are weighted in terms of severity of restriction in activity. The final score represents a total of the four categories to give a physical dimension score of activity restriction, which is a combination of disability and level of handicap.

The FLP has been found to be both a valid and reliable instrument (De Bruin, White, Stevens, and Diederiks, 1992). Internal consistency of the four physical categories ranges from 0.73 - 0.83 (Johnston, Wright and Weinman, 1993).

The Structural Profile Inventory (SPI), (Lazarus, 1989)

This questionnaire was used to measure the modality preferences of respondents. It was chosen because it is relatively quick and easy to answer, in contrast to a much longer and detailed questionnaire (15 pages) the Multimodal Life History Inventory also designed to measure modality preferences (Lazarus and Lazarus, 1991). The SPI is a 35 item self-report questionnaire. Respondents are asked to rate their response to statements relating to modality tendencies on a seven-point Likert scale (see appendix). Final scores are calculated for each of the seven modalities. They can range from 5 - 35 points.

The SPI has been found to be a valid instrument in predicting psychopathology (Herman, Cave, Kooreman, Miller, Welch, Kowalski, and Jones, 1995). Studies have also shown it to be internally consistent (Herman, 1992; Landes, 1991).

Coping Orientations to Problems Experienced (COPE), (Carver, Scheier and Weintraub, 1989)

The COPE was chosen because it is a well used and validated measure that has been used in previous studies on adjustment issues and amputation (Livneh et al, 1999). This allowed for greater comparison of findings between studies. The dispositional version of the COPE was used in this study. It is a 60 item self-report questionnaire that measures individuals coping styles in response to stressful or difficult situations. It requires respondents to rate their response to statements on a four-point scale. It consists of 15 subscales of different coping responses.

Internal consistency of each of the scales exceeds 0.6, except for mental disengagement. This scale is likely to be less internally consistent. Test-retest reliability for the dispositional version over 6 and 8 week periods ranged from 0.42 - 0.89 for the different scales. Therefore, the coping styles measured by this instrument are fairly stable. Construct validity is also satisfactory (Carver et al, 1989).

The Hospital Anxiety and Depression Scale (HAD), (Zigmond and Snaith, 1983).

This measure was chosen because it is a brief assessment of anxiety and depression. It is also more useful than the Beck Depression (Beck, 1978) or Anxiety Inventory (Beck, 1990; 1987) in that does not include items that could be symptomatic of both physical and emotional

disorders (e.g. dizziness and headaches). This is a particularly important feature considering the number of people with diabetes who have amputations because of circulatory problems. Dizziness and poor sleep could be as much symptoms of diabetes as they are of anxiety and depression.

The HAD consists of 14 items which respondents rate on a four-point scale. Total scores are calculated for the two sub-scales anxiety and depression. Depression and anxiety ratings of seven or less are considered to be non-cases. Scores of 8 - 10 are doubtful and scores of 11+ are definite cases.

Internal consistency for the anxiety items ranged from 0.41 - 0.76 and for depression items it was 0.30 - 0.60. The range of values suggests that some items on the scale could be measuring concepts other than anxiety or depression. Inter-rater reliability has been found to be 0.70 for depression and 0.74 for anxiety. Concurrent validity was significant with psychiatric assessments (0.70 for depression and 0.74 for anxiety).

The Life Satisfaction Index A (Neugarten, Havinghurst and Tobin, 1961)

This questionnaire was chosen because it was short and relatively easy to answer. It is a 20 item self-report measure of life satisfaction. Respondents are asked to indicate where they agree, disagree, or don't know, with each statement. A total score is calculated and used as an index of satisfaction.

Concurrent validity has been reported to be 0.52. Criterion validity has been found to be 0.64 (Bowling, 1997). Internal consistency is reported to range from 0.70 - 0.76 (Dobson, Powers, and Keith, 1979).

2.4 Apparatus

To record the interviews a small dictaphone was used to tape respondent's views.

2.5 Procedure

Patients with appointments with prosthetists were asked by their prothetist whether they would like to take part in a research project on adjustment to amputation. They were given an information sheet (appendix 7) by their prosthetist before deciding. This happened during their appointment and consultation with the prosthetist. The recruitment of patients took place on different days of the week over a period of 4 months. If they agreed to take part the prosthetist would bring the researcher into the fitting room and then leave. Patients were then asked to sign a consent form (appendix 6) saying that they had read and understood the information sheet and were happy to participate. Respondents were given a blank copy of the questionnaires to follow as the researcher read through each one and recorded their responses on separate copies. If a suitable private room was not available respondents were given the questionnaires to fill out on their own.

Participants were first asked to give some personal details such as date of birth, type of amputation, reason for, and the time since their operation. They were then asked to indicate their level of disability by answering The Functional Limitations Questionnaire. After this the order of presentation for the questionnaire was; The Hospital Depression and Anxiety Scale,

The Structural Profile Inventory, the COPE, and The Life Satisfaction Questionnaire. Participants were then asked to comment on their experience of amputation with reference to rehabilitation and what they found helpful, what was not so helpful and if anything could have been improved or changed to make it better. Their responses were tape recorded.

The questionnaires were administered during the person's appointment rather than before or after as this was thought to be more convenient for the patient. An appointment to the limb fitting centre can involve a lot of waiting while the prosthetist takes the patient's limb away to adjust, repair or fit a new one. Rather than delay patients after their appointment it was considered better for them to participate while they were waiting during their appointment.

Participants from the in-patient unit were approached by the researcher directly. Prior to this the researcher had visited the unit to talk to the staff about the research project and copies of the information sheet were left for staff to put up around the unit and give to patients. If they agreed to take part, where possible they were taken to a private room to participate. From this point the procedure was the same as for patients visiting the limb fitting centre. If they did not have time to go through the questionnaires with the researcher (e.g. they were expecting visitors) or there was no private room they were given a set of questionnaires to fill out in their own time, and these were collected later by the researcher.

2.5 Ethical Considerations

There were five questionnaires for participants to complete in this study. This could take up to 40 minutes to complete. In some cases people were waiting a long time for fittings and adjustments to their leg and were not unduly inconvenienced. However, it was quicker for

respondents to go through the questionnaires with the researcher and where privacy allowed this was the preferred procedure.

Not all participants took part in the recorded interview either through choice or insufficient privacy. Participants were approached by their prosthetist to find out if they would like to take part in the research. Their participation did not effect the quality of care or services they received from the centre. The researcher was accommodated in the prosthetists room while carrying out the research. Individual participants and their responses were kept confidential and anonymous. Participants consent forms and personal details were kept completely separate from completed questionnaires and were only identified by a participant number.

With regards to the sensitivity of some of the questionnaires, participants were assured that they could withdraw from the research at any time if they found that the questions were too personal or distressing. Participation was voluntary and it was not obligatory to complete the whole set of questionnaires or interview. If any of the respondents had shown obvious signs of distress or depression the researcher would have stopped their participation in the research. They would have been advised to contact their General Practitioner who would be able to offer them further help and support.

All taped interviews were kept and transcribed by the researcher. Transcripts are not identified in any way so as to protect participants anonymity.

2.6 Data Management

2.6.1 Quantitative Data

Associations between coping strategies, sociodemographic variables and indicators of adjustment difficulties (depression, anxiety and life satisfaction) were examined using Person's r (two-tailed) with significance reported at the $p < 0.05$ level. This was also the case for associations between modalities and sociodemographic variables and indicators of adjustment difficulties. The significance level was chosen because associations between sociodemographic variables and these other variables have already been well established in previous research. Associations between modalities and coping strategies were examined using Person's r (one-tailed) with significance reported at the $p < 0.01$ level. As the hypothesis behind this association had not been investigated in previous research and it involved a lot of analyses a more stringent significance level was used to protect against a Type 1 error. Differences between participants were analysed using Mann-Whitney because of small number in comparative groups. Comparisons between the means of a standard population and the sample population for coping strategies were made using the independent t -test (two-tailed). Multiple regression analysis was used to examine the strength of modalities as predictor variables for coping strategies, and the strength of modalities and coping strategies as predictor variables for anxiety, depression and life satisfaction.

2.6.2 Qualitative Data

Qualitative data from the short interviews was analysed using content analysis (Strauss and Corbin, 1998). The transcripts from the taped interviews were scanned paragraph by paragraph for themes related to the research hypotheses. Relevant paragraphs were coded according to the themes that they represented. The themes were then divided into three

categories that corresponded with the research hypotheses. The categories were: 'Things that are helpful', 'Things that are unhelpful', and 'The experience of having an amputation and artificial limb'.

To validate the analysis of the transcripts an inter-rater reliability check was used with two raters and a percentage level of agreement was calculated for the analysis. Each theme was presented with the examples of text from the transcripts that related to the theme and the raters were instructed to rate whether they thought the examples were representative of the themes or not. The examples of text that the raters agreed were representative of the themes were kept and those that were not felt to be representative were taken out.

3. Results – Quantitative

3.1 Sociodemographic variables

Hypothesis 1.

“Some sociodemographic factors such as age, gender, time since amputation, reason for amputation, and level of physical disability, will be related to different coping strategies and modalities”.

Gender and time since amputation were the only two sociodemographic factors found to be related to particular coping strategies and modalities. There were no significant differences between participants on coping strategies or modality preferences with regards to their marital status, reason for amputation, and age.

3.1.1 Gender differences

There was one significant difference between men and women on modality preference. Women rated themselves as less behaviour orientated than men ($U = 86.50$, $N_1 = 29$, $N_2 = 11$, $p = 0.025$, two-tailed).

There were only two significant differences between men and women on coping strategies. Women used denial ($U = 78.50$, $N_1 = 29$, $N_2 = 11$, $p = 0.04$, two-tailed) and behavioural disengagement ($U = 73.00$, $N_1 = 29$, $N_2 = 11$, $p = 0.026$, two-tailed) more than men.

3.1.2 Time since amputation

Differences in modality preferences between short and long term amputees were found for two modalities. Amputees of less than five years showed less preference for cognition ($U = 125.00$, $N_1 = 18$, $N_2 = 22$, $p = 0.048$, two-tailed) and interpersonal modalities ($U = 107.50$, $N_1 = 17$, $N_2 = 22$, $p = 0.023$, two-tailed) when compared with amputees of over five years.

There were two significant differences with regards to time since amputation and coping styles. Amputees of less than five years reported less use of suppression of competing activities ($U = 110.50$, $N_1 = 17$, $N_2 = 21$, $p = 0.045$) and planning ($U = 97.50$, $N_1 = 17$, $N_2 = 21$, $p = 0.016$) than amputees of five years and over.

Correlations (see table 1) between coping styles and socio demographic variables show that planning is a strategy associated with length of time since amputation ($r = 0.440$, $n = 38$, $p = 0.006$, two-tailed). Recent amputees tend to use planning less as a coping strategy than longer-term amputees. Suppression of competing activities is also more associated with time since amputation ($r = 0.417$, $n = 38$, $p = 0.009$, two-tailed) and planning ($r = 0.554$, $n = 38$, $p = 0.000$, one-tailed). So longer-term amputees are more likely to use planning and focus on one difficult event at a time than recent amputees.

3.2 Coping Styles

Hypothesis 2.

“Some coping strategies will be related to levels of depression, anxiety and life satisfaction”.

3.2.1 Depression

People who used emotional ways of coping (i.e. focusing and venting on emotions) were also more likely to score higher on the depression scale ($r = 0.455$, $n = 38$, $p = 0.004$, two-tailed). However, humour appears to protect against depressive symptoms. The more a person used humour as a coping strategy the lower their score on the index of depression ($r = -0.484$, $n = 38$, $p = 0.002$, two-tailed). None of the participants in this study scored within the range of caseness for depression and only two scored within the doubtful range ((8-9,) mean; 2.70, S.D; 2.06, n ; 40).

3.2.2 Anxiety

Anxiety was higher for people who tended to cope with stress by using denial ($r = 0.518$, $n = 38$, $p = 0.001$, two-tailed) focusing on their emotions ($r = 0.714$, $n = 38$, $p = 0.000$, two-tailed), and mentally disengaging ($r = 0.561$, $n = 38$, $p = 0.000$, two-tailed) from the stressor.

3.2.3 Life Satisfaction

Life satisfaction was positively correlated with positive reinterpretation and growth ($r = -0.448$, $n = 38$, $p = 0.005$, two-tailed), but negatively correlated with mental disengagement ($r = 0.419$, $n = 38$, $p = 0.009$, two-tailed). Amputees who were able to be positive about stressors and try to learn something from it were more satisfied with life. Those who tried not to think about difficulties tended to be less satisfied with life.

3.3 Modalities

Hypothesis 3.

“Some Modalities will be related to levels of depression, anxiety and life satisfaction”

Table 2. Correlations between sociodemographic variables, indicators of distress and modalities

	Behaviour	Affect	Sensation	Imagery	Cognition	Interpersonal	Drugs/ Health
Age	-0.316	-0.098	-0.336	-0.086	-0.139	-0.001	0.39
Time since amputation	0.137	-0.212	-0.08	0.045	0.345	-0.208	0.082
Life satisfaction index	<u>0.565</u>	-0.207	0.263	0.094	0.304	-0.134	0.028
Anxiety	-0.205	<u>0.509</u>	-0.027	0.102	0.002	-0.158	-0.235
Depression	-0.355	0.03	-0.306	0.089	-0.034	-0.15	-0.082
Physical limitations	-0.382	0.316	-0.137	-0.256	-0.317	0.218	0.044

Note: Significant correlations at the 0.01 level (two-tailed) are in bold and underlined

3.3.1 Depression

There were no significant correlations between depression scores and modality scores.

3.3.2 Anxiety

There was also a positive correlation between Affect and anxiety ($r = 0.509$, $n = 39$, $p = 0.001$, two-tailed). This suggests that the more people tended towards scoring higher on Affect the higher their anxiety rating. However, no one in this sample scored at the level required for caseness of anxiety in accordance with the test scoring system.

3.3.3 Life Satisfaction

The Behaviour modality was positively correlated with life satisfaction ($r = 0.548$, $n = 40$, $p = 0.000$, two-tailed, see table 3). The more preference that amputees showed towards the behaviour modality the higher their life satisfaction score.

3.4 Relationship between Modalities and Coping Styles

Hypothesis 4.

“Modalities will be related to coping strategies”.

3.4.1 Active Coping

Cognition ($r = 0.617$, $n = 38$, $p < 0.001$, two-tailed) and Behaviour ($r = 0.426$, $n = 38$, $p = 0.008$, two-tailed) modalities were significantly correlated with active coping (see table 3). Three modalities (Cognition, Behaviour and Drugs/health) contributed significantly to explaining the variance in reports of active coping ($F_{3,34} = 8.925$, $p = < 0.005$. Adjusted R square = 0.391). Of the three modalities, cognition was the only significant predictor of active coping (see appendix 8). The more cognitively orientated the person was the more likely they were to use active ways of coping.

3.4.2 Positive Reinterpretation

Amputees showing strong preferences for Behaviour ($r = 0.625$, $n = 38$, $p < 0.001$, two-tailed) and Imagery ($r = 0.436$, $n = 37$, $p = 0.007$, two-tailed) were more likely to make positive reinterpretations of events and try to grow from the experience. Three modalities (Behaviour, Cognition and Imagery) contributed significantly to explaining the variance in reported use of this coping strategy ($F_{3,33} = 8.621$, $p = < 0.005$. Adjusted R square = 0.388). Behaviour was the only modality that significantly predicted positive reinterpretation of events and growth (see appendix 8). Respondents who rated themselves as more Behaviour orientated were more likely to cope with distressing events by using positive reinterpretation and reflecting on what they had learnt from the experience. Positive reinterpretation and growth was also significantly correlated with active coping ($r = 0.602$, $n = 38$, $p < 0.001$).

Table 3. Correlations between the COPE and Structural Profile Inventory subscales. Significant correlations are reported in bold and underlined ($p < .01$, two-tailed).

	active coping	planning	seeking instrumental social support	seeking emotional social support	suppression of competing activities	turning to religion	positive reinterpretation & growth	restraint coping	acceptance	focus on & venting emotions	denial	mental disengagement	behavioural disengagement	alcohol / drug use	humour	Behaviour	Affect	Sensation	Imagery	Cognition	Interpersonal	Drugs / health	N
active coping	1.000																						38
planning	<u>.646</u>	1.00																					38
Seeking instrumental social support	<u>.638</u>	<u>.496</u>	1.00																				38
seeking emotional social support	<u>.452</u>	259	<u>.572</u>	1.00																			38
suppression of competing activities	<u>.678</u>	<u>.554</u>	<u>.605</u>	<u>.537</u>	1.00																		38
turning to religion	-.012	160	-117	.240	.076	1.00																	38
Positive reinterpretation and growth	<u>.602</u>	<u>.464</u>	319	.384	.343	.124	1.00																38
restraint coping	<u>.461</u>	.293	.288	.382	<u>.594</u>	-.110	227	1.00															38
acceptance	<u>.451</u>	.365	<u>.423</u>	<u>.525</u>	<u>.436</u>	-.099	298	.406	1.00														38
focus on and venting of emotions	.263	.222	.395	<u>.641</u>	<u>.510</u>	.379	.105	.274	.410	1.00													38
denial	.025	-.027	.058	.363	.263	.316	-.192	.281	.171	<u>.702</u>	1.00												38
mental disengagement	.128	.326	.375	<u>.476</u>	.402	.193	.023	.309	<u>.641</u>	<u>.598</u>	<u>.418</u>	1.00											38
behaviour disengagement	-.053	-.082	.019	.291	.235	.224	-.115	.221	.217	<u>.513</u>	.345	<u>.458</u>	1.00										38
alcohol or drug use	.156	.231	.162	.152	.157	.033	.082	.080	.101	.203	.041	.027	.045	1.00									38
humour	<u>.423</u>	.149	.223	.246	.125	.019	<u>.741</u>	.091	.144	-.077	-.186	-.178	-.154	-.001									38
Behavioural	<u>.426</u>	.277	.273	.185	.132	-.292	<u>.625</u>	.039	-.062	-.145	-.356	-.273	-.231	-.125	<u>.479</u>	1.00							38
Affect	.192	.229	<u>.451</u>	<u>.637</u>	.413	.221	.188	.124	.364	<u>.538</u>	.345	<u>.504</u>	.400	-.069	.171	.049	1.000						37
Sensation	.358	.262	<u>.449</u>	.379	.410	-.056	.373	.067	.140	.101	-.071	.088	-.052	-.238	.337	<u>.669</u>	<u>.483</u>	1.000					38
Imagery	.247	.364	.140	.310	.258	.159	<u>.436</u>	.216	.172	.245	-.025	.193	.206	.149	.088	<u>.435</u>	.250	.303	1.00				37
Cognition	<u>.617</u>	<u>.631</u>	<u>.485</u>	.248	<u>.416</u>	-.039	.394	.344	.219	-.050	-.220	-.051	-.326	.257	.203	<u>.406</u>	.099	.396	<u>.449</u>				38
Interpersonal	.211	.055	.298	.416	.163	.217	.251	-.021	.146	.190	.060	-.047	-.118	-.147	.345	.141	.180	.300	.120	.127	1.00		37
drugs or health	.392	.240	.348	.348	.246	.019	.303	.177	.292	.154	-.044	.118	.014	-.197	.101	.320	.083	.321	.138	.297	.387	1.00	38

Taken together this cluster of correlations suggest that amputees who preferred to think through things and keep busy were more likely to use positive reframes, look for the benefits of change and take an active approach in adjusting to a stressful event.

3.4.3 Emotional Social Support

Respondents who scored highly on Affect ($r = 0.637$, $n = 37$, $p < 0.001$, two-tailed) were more likely to seek emotional social support. Three modalities (Affect, Sensation and Interpersonal) contributed significantly to explaining the variance in reported use of seeking emotional social support ($F_{3,33} = 11.594$, $p = < 0.005$. Adjusted R square = 0.469). In particular, Affect and Interpersonal modalities were significant predictors of a participant's use of emotional social support (see appendix 8). So, people who place strong importance on friendships and social interaction, and are quite sensitive to their own emotional state are more likely to use coping strategies that involve looking for sympathy or emotional support from someone.

3.4.4 Seeking Instrumental Social Support

Affect ($r = 0.451$, $n = 37$, $p = 0.005$, two-tailed) and Sensation ($r = 0.449$, $n = 38$, $p = 0.005$, two-tailed), along with Cognition ($r = 0.485$, $n = 38$, $p = 0.002$, two-tailed) were also significantly related to seeking instrumental social support. These modalities contributed significantly to explaining the variance of responses for seeking instrumental social support ($F_{3,33} = 6.890$, $p = < 0.005$. Adjusted R square = 0.329). Significant variables in this model were Affect and Cognition (see appendix 8). Therefore, amputees who reported that they tended to think and reason through things, and were quite attentive to their feelings and emotions, were more likely to try to get support by seeking assistance and information from others about what to do.

3.4.5 Suppression of Competing Activities

Cognition ($r = 0.416$, $n = 38$, $p = 0.009$) was significantly correlated with suppression of competing activities. However, in combination with two other modalities (Affect and Sensation) which were highly correlated with this coping strategy, cognition did not contribute significantly to explaining the variance in this coping style at the $p < 0.005$ level of significance.

3.5 Additional Results

3.5.1 Gender differences

A comparison of mean scores shows that on average men were more satisfied with life (mean; 27.89, SD; 4.59, $n = 29$) than women (mean; 21.81, SD; 8.54, $n = 11$). This was a statistically significant difference ($U = 91.50$, $N_1 = 29$, $N_2 = 11$, $p = 0.038$). Scores on measures of anxiety and depression do not differ greatly. The gender difference on life satisfaction could be related to levels of disability. Overall, female respondents rated their level of physical limitation (mean; 1.66, SD; 1.02, $n = 11$) higher than male participants (mean; 0.63, SD; 0.74, $n = 29$). Using a Mann-Whitney the difference between men and women on levels of physical limitation is statistically significant ($U = 62.50$, $N_1 = 29$, $N_2 = 11$, $p = 0.002$, two-tailed). There were no significant differences between men and women for age or length of time since amputation.

3.5.2 Time since amputation

When the sample was split into two groups according to time since amputation (less than five years and more than five years) a number of significant differences were observed. There was

a significant difference in reports of physical limitations ($U = 52.50$, $N_1 = 18$, $N_2 = 22$, $p = 0.000$), two tailed). Amputees of less than five years rated themselves as more limited (mean; 1.55, SD; 0.93, n; 18) than amputees of five years or more (mean; 0.38, SD; 0.53, n; 22). Furthermore, amputees who had their amputation less than five years were significantly less satisfied with life than amputees who had had their amputation over five years ago ($U = 122.50$, $N_1 = 18$, $N_2 = 22$, $p = 0.039$, two-tailed). Although, the overall life satisfaction scores for both groups were within normal limits.

3.5.3 Coping Strategies

As a group, this sample of amputees only differed from a standard population sample (Carver et al, 1989) in their use of mental disengagement, focus on and venting of emotions, and seeking emotional support.

Table 4: Differences between participants coping style scores and a standardised population.

	t-value	df	Significance (two-tailed)	N	Standardised mean score	Mean score
Active Coping	1.109	37	0.274	38	11.89	12.39
Planning	1.197	37	0.239	37	12.58	11.97
Seeking instrumental and social support	1.944	37	0.059	38	11.5	10.34
Seeking emotional and social support	4.044	37	0	38	11.01	8.86
Suppression of competing activities	0.669	37	0.508	38	9.92	9.6
Turning to religion	1.424	37	0.163	38	8.82	7.68
Positive reinterpretation and growth	0.211	37	0.834	38	12.4	12.5
Restraint coping	0.596	37	0.555	38	10.28	10.02
Acceptance	0.266	37	0.792	38	11.84	11.73
Focus on and venting of emotions	3.425	37	0.002	38	10.17	8.34
Denial	1.08	37	0.287	38	6.07	6.6
Mental disengagement	3.421	37	0.002	38	9.66	8.18
Behavioural disengagement	0.014	37	0.989	38	6.11	6.1

Amputees used mental disengagement significantly less as a way of coping ($t = 3.421$, $df = 37$, $p = 0.002$, two-tailed) than the standard sample of respondents. They also used focusing on and venting of emotions ($t = 3.425$, $df = 37$, $p = 0.002$, two-tailed) and seeking emotional social support ($t = 4.044$, $df = 37$, $p = 0.000$, two-tailed) less.

The maximum possible score for any coping style is sixteen and the lowest score is four. Overall mean scores for the current sample of participants show that the most favoured coping styles were active coping (mean; 12.39, SD; 2.80, n; 38), planning (mean; 11.97, SD; 3.12, n; 38), positive reinterpretation and growth (mean; 12.50, SD; 2.92, n; 38), humour (mean;11.50, SD;3.45, n; 38) and acceptance (mean;11.73, SD; 2.39, n; 38). Lesser used styles were denial (mean; 6.60, SD; 3.05, n; 38), behavioural disengagement (mean;6.10, SD; 2.08, n; 38) and drugs or alcohol (mean;5.76, SD; 2.87, n; 38).

3.5.4 Modalities

As a group, the amputees in this study showed a preference towards the Interpersonal modality, with an average score of 29.35 out of possible maximum of 35 (see table 5).

Table 5: The mean scores of the seven modalities

	Mean	SD
Behaviour	20.77	6.89
Affect	25.3	4.76
Sensation	26.34	5.13
Imagery	25.41	4.97
Cognition	25.75	5.12
Interpersonal	29.35	5.19
Drugs	26.3	5.75

Thirty-five is the highest total score for all the modalities, except for behaviour which is 28. Therefore, relative to the maximum possible scores, Affect was the least preferred modality. However, the average overall score for all of the modalities was quite high and differences quite small.

3.6 Summary of results

Of all the sociodemographic factors recorded only gender and time since amputation were significantly related to particular coping strategies and modalities. Female participants rated themselves as more behaviour orientated than men and used denial and behavioural disengagement coping strategies more than men. Respondents who had been amputees for more than five years showed greater preferences for cognition and interpersonal modalities than amputees of less than five years. Shorter term amputees reported significantly less use of suppression of competing activities and planning coping strategies than longer term amputees.

Some of the coping strategies were related to levels of depression, anxiety and life satisfaction. Emotional coping strategies (e.g. focusing and venting of emotions) were associated with higher scores on the depression scale. Whereas, the use of humour was associated with low depression scores. Denial, focusing on emotions and mental disengagement were all associated with higher levels of anxiety. Positive reinterpretation and growth was correlated with high levels of life satisfaction, but mental disengagement was associated with low levels of life satisfaction.

Some of the modalities were found to be related to levels of anxiety and life satisfaction, but none of them were related levels of depression. Specifically, there was a positive relationship

between Affect and anxiety, and, preference for the Behaviour modality was associated with greater life satisfaction.

There were a variety of correlations between modality preferences and use of coping strategies. The more cognitively orientated a person was the more likely they were to use an active coping strategy. The greater a person's preference was for the Behaviour modality the more likely they were to use positive reinterpretation and growth as a coping strategy. The stronger a respondent's preference was for Affect and Interpersonal modalities the greater the likelihood that they would use emotional social support as a coping strategy. Participant's who showed a preference for Affect and Cognition modalities tended to seek emotional social support more than other respondents.

4. Results – Qualitative

4.1 Things that are helpful.

Table 1: Themes related to what people felt helped when they had their amputation

Themes	Definition	Number of people mentioning the theme
Contact with other amputees	<i>The benefits of being able talk to other amputees</i>	4
Practical help from professionals	<i>Getting services from health and social services</i>	6

Percentage agreement =100%

Being with other amputees

Comments during interviews that were about the importance of being with amputees seemed to relate to the two coping strategies of seeking emotional and instrumental social support. For example one person spoke of the comparison between having their operation in a private hospital where there was no contact with other amputees and then coming for rehabilitation at the centre where they were able to meet lots of other people with amputations:

“Possibly the only drawback with that was I wasn’t with other amputees, which I’ve found since helps a lot. Being with other people in the same situation, seeing that there are other people in the same situation”

The other value of being with other amputees was being able to find out about the services that were available, that is, more instrumental support in the form of advice and information:

“And its not very often that a limbless person will be in contact with a lot of other limbless people to know, to network and what you know between yourselves... I do a lot with other limbless people so I can see what, what limbs and things, and arms and feet they’re getting”

“I’ve spoken to a couple of guys here, no one, they’re actually having fittings or whatever, no-one came to speak to them in the hospital. So basically that would be a real help because they think

well I'll never be able to ride push bike again, won't be able to do this won't be able to do that, you know".

4.1.2 Practical Help from Professionals

Health and social services professionals were also mentioned as a source of instrumental support particularly with regards to helping people maintain their independence at home.

"An occupational therapist and a physiotherapist came and looked at the house before I came home to check that everything was all right for me to go there"

"I mean the local services they even cut down a hedge, and made an entrance place by the side of the house onto the lawn so a car could be driven in and I could get into it. And I got, what have I got? A new wheelchair and they came round and for the first month I had somebody in, to see me, to get me up in the morning and bath and that sort of thing."

4.2 Things that are unhelpful

Theme	Definition	Number of people who mentioned the theme
Fitting and repair time	<i>The time it takes for prosthetic services to fit or repair artificial limbs</i>	7

Percentage agreement = 84%

The main complaint levied against services was the waiting time during appointments with a prosthetist and also the overall time it took for limbs to be repaired or fitted.

"You come in to just have an alteration or final fitting and you be sitting in here for an hour and a half and then he'll come and try it and he'll say oh I'm just gonna make an adjustment, back in five minutes. I know it's not their fault they're busy with they're buried in work and another hour goes by. And I've been here all day and basically had nothing done, you know".

Although people were unhappy about the waiting time they were still quite understanding of the pressures that prosthetists and the service in general was under. The dissatisfaction

seemed to be related to having to stay in one place and not being to get around while their leg(s) where elsewhere. One participant spoke of how disabling the experience could be:

“the length of time it takes to get repairs done, new legs made, whatever, that, that can make you feel quite disabled. I only ever feel bad about my disability when I’m here and that’s not necessarily the fault of the people who work here but just the actual environment”.

Another person felt that their dislike of having to wait around and knowledge that any repairs or fittings would take time, meant that they were more likely to accept the prothesis they were given even though they felt they could have asked for more:

“So you accept less than you should because it takes so long to do anything”.

4.3 The experience of having an amputation and artificial limb

Theme	Definition	Number of people who mentioned the theme
Access to and knowledge of services.	<i>Being able to access a full service and having knowledge of what is available.</i>	6
Emotional aspects.	<i>Emotional reactions to amputation and disability.</i>	10
Minimal limitations or impact on lifestyle.	<i>Staying active and getting on with life.</i>	7

Percentage agreement, 84%

4.3.1 Access to and knowledge of services.

Several interviewees wanted all amputees, regardless of age and recency, to be better informed about the range of limbs and specialist services available. This is similar to an active coping or

active information seeking. One interviewee was particularly concerned for people to know more about the practical support services available:

“Like go to shop-ability sort of thing and so many things. Now I learnt all these little things from my next door neighbour. Now why should I have to learn from the next door neighbour? You see it's wrong. I know, a lot of things you can't ... They do a lot of good things, but just the same something could be...more information would be a big big thing, you know”.

Other people believed that recent amputees needed to be given more information about the different types of limbs available and encouraged to take more active role their treatment. There was concern that services should routinely inform all amputees about the range of services and prothesis available to them, rather than this kind of knowledge simply being imparted by word of mouth between amputees during visits to the fitting centre. For example:

“Unfortunately, he who shouts the loudest gets the best and I'm, at my age I'm prepared to shout. And newer amputees don't, I feel sorry for them. I've even sat in here and I've, when the prothetist's has gone out, in the past I've done it, I've said, you know, do you know you can get this done, do you know they've got that, “have they, I didn't know that”, then I get out the room quick before they start asking. Cos it's the only way you're gonna find out isn't it.”

“I suppose another criticism would be maybe not so much now but maybe in the past you don't, as a patient, you don't see what's available. Like if you go and buy a car you can go and look at all the different cars. When you come into this situation you look to the doctors and fitters and they tell you what you will have basically, they will say well this is available, this is the best and that's it. You don't have a, no showrooms, there are no showrooms, no catalogues, and its not very often that a limbless person will be in contact with a lot of other limbless people to know, to network and what you know between yourselves”.

4.3.2 Emotional aspects

Responses referring to the emotional aspects of amputation were quite varied. They included comments about reactions and difficulties in the period just following amputation and as well as more ongoing, situation specific feelings of disability. For example, in the period following amputation one person remarked:

“and it would be hard for the first few months even a year. Everyone’s gonna, everyone feels the same, you get real despondent after the first year because nothing goes right basically. Or you think nothing’s going right. The legs you know, you keep changing shape and the stump whatever, but first twelve months are the worst”.

With regards to specific situations that can leave a person feeling more disabled than usual one person spoke about how it felt being without their limb and not being about to walk because there were no other aids, such as crutches, immediately to hand.

“The fact that I’m sat here now and I’ve got no leg, no crutches or anything. If I want to go to the toilet or if I wanna do anything I’m completely trapped... it turns you from being very sort of independent and able to being disabled really, not having any say in what you can do or not do... but certainly I feel that it means that I don’t get the best care possible because I get very stressed about being here and I just wanna go”.

4.3.3 Minimal limitations or impact on lifestyle.

Many respondents in this study led full and active lives. Some people were probably more active than the general population. For many, more longer term amputees, having an amputation was not seen as a disabling condition. For example:

“and took up golf nine years ago, now one of the best amputee golfers in the world, got a single figure handicap and what with the new rotational ankles and everything its getting better and better for me”.

“I lead a full active life,... You know I do all the things around the house. I’m married I’ve got children and I do my gardening when I can, this sort of life. I don’t want the legs to stop me... In the old days they say well you shouldn’t be climbing over walls and that. And I say no, you make me legs to lead my life, I’m not gonna lead my life for my legs”.

If some activities did prove difficult it was possible to compensate for them and still enjoy a variety of hobbies. For instance:

“I’m not overly concerned about mobility. Should of been. You know I keep looking at this amputee football team and disabled football and all that, water skiing that guys are doing , but I go rock

climbing and stuff. So I ain't really worried. It's just a bit more awkward. Just have to use a bit more arm strength rather than leg strength".

5. DISCUSSION

5.1 Sociodemographic factors related to coping strategies and modalities

5.1.1 Gender and Time since amputation

Overall, the findings from this study showed some differences between men and women, and older and newer amputees. On average, women and more recent amputees indicated that they were less satisfied with life and had a higher level of disability than men and older amputees. There were also differences in their use of different coping strategies. Women used denial and behavioural disengagement more than men and newer amputees used planning and suppression of competing activities less than older amputees. With regards to preferences in the different modalities, women generally rated themselves as less behaviour orientated than men and newer amputees showed less preference for cognition and interpersonal modalities compared to older amputees.

5.2 Use of coping strategies and their relationship with levels of depression, anxiety and life satisfaction

As a group, respondents used positive reinterpretation and growth, active coping, planning, acceptance and humour most often in times of stress. They rarely used denial, behavioural disengagement and drugs/alcohol as a way of coping with difficult situations. In comparison with a standardised population, this sample of amputees used mental disengagement, focusing on and venting of emotions, and emotional social support significantly less as ways of coping. The more a person tried to cope with difficulties by reinterpreting them in a positive way and reflecting on what they gained from the situation, the higher their life satisfaction rating. On the other hand, the more someone tried to avoid or distract themselves from what was

distressing them (i.e. mental disengagement), the less likely they were to be satisfied with life and the higher their anxiety rating. Anxiety was also higher for people the more they tried to deny the reality of the situation. Awareness of one's distress and expression of emotion was another factor associated with anxiety and depression. Rates of depressive symptoms were much lower for people who used humour more and joked about the problem.

5.3. Modality preferences and their relationship with anxiety and life satisfaction

With regards to modality profiles, average modality scores showed that this sample of participants had a strong leaning towards the Interpersonal modality. In general, people saw themselves as quite sociable and enjoyed the company of others. The weakest modality was Affect, an indicator of how emotional people thought they were. The stronger a person's preference for the Affect modality the higher their anxiety rating. Whereas, the more Behaviour orientated a person was the more satisfied they were with life.

5.4 Relationships between coping styles and modalities

Positive reinterpretation and growth was a coping strategy associated with higher life satisfaction scores. The Behaviour modality was also related to higher life satisfaction scores and was found to be a significant predictor variable in explaining a person's use of positive reinterpretation and growth as a coping strategy. Together, Cognition, Imagery and Behaviour modalities explained thirty-eight percent of the variance in people's reported use of this coping strategy.

Seeking emotional social support was a coping strategy associated with higher ratings on scales of anxiety and depression. Affect and Interpersonal scales were found to be significant

variables in predicting someone's use of this coping strategy. Together with the Sensation modality, Affect and Interpersonal scales accounted for forty-seven percent of the variance in scores for seeking emotional social support as a way of coping.

5.5 How do the findings relate to previous research?

5.5.1 Explanations for gender differences in the results

In previous studies there have been no reports of gender differences in adjustment amongst amputees, but differences have been found between newer and older amputees (Rybarczyk et al, 1995; Livneh et al, 1999) and levels of physical limitation (Williamson, et al, 1994). The difference in life satisfaction scores between men and women in this study appeared to be related to levels of disability among female respondents. It is possible that the sample of women who took part in this study was unrepresentative of the wider population. The sample included a disproportionate number of female respondents who were currently experiencing more physical difficulties than usual.

One reason for this could have been the setting from which people were invited to take part in the research, although other studies have used similar recruitment methods and not found the discrepancy (Rybarczyk, et al, 1995, Gallagher and Maclachan, 1999). Comments from the interviews showed that some people only came to the fitting centre when they were having problems and would otherwise not visit the centre for unless they had a routine appointment every few years. For example, two women had recently (in the past year) had problems with stump infection and as a result needed to be fitted for a new limb. There were also three other respondents who were recruited from the in-patient unit and were still having intensive

rehabilitation. Having at least five women from a group of only 11 who were experiencing more physical limitations would have affected the average level of disability for the whole group of female respondents.

5.5.2 Results supporting previous research findings

Other findings did support some of the conclusions from previous research. As with Livneh et al's study, cognitive disengagement (mental disengagement and denial) and emotion focused ways of coping were associated with levels of distress and possible adjustment difficulties. Also, using positive reinterpretation and growth as a coping strategy had a beneficial impact on mental well-being. Participants were significantly more satisfied with their life the more they used this strategy. However, unlike Livneh et al (1999) there was no evidence from this study to suggest that seeking emotional social support was especially related to adjustment or low levels of distress. In fact, it was a coping strategy that was used significantly less when compared with norms from a standard population. Gallagher and MacLachlan (1999) found that seeking emotional social support was related to higher levels of despair.

5.6 The role of social support in adjustment to acquired physical disability

Comments from the interviews could provide some clues as to the benefits or lack of benefit from social support. Several amputees felt that talking to other amputees was very helpful. They could share their difficulties with each other and newer amputees could talk about their fears for the future with older amputees. This is an issue which relates to the criticism levied against Livneh et al (1999), about the possibility that recruiting participants from amputees support groups meant the sample was generally better adjusted and scored lower on measures of depression than an average amputee.

A more peculiar issue that relates to the use of social support is the preference which most people showed for the Interpersonal modality. This is an indicator of how 'people orientated' a person is, how much they value friendships and social activities. Logically, one would assume that if the most preferred modality was the Interpersonal scale, then it should follow that seeking social support would also be a popular coping strategy. However, the results showed that even though it was not one of the least favoured strategies, people still used it less than a standard population. One explanation for this could be that the norms from the standard population are not representative of the wider general population and do not constitute a reliable comparison group. The participants who made up Carver et al's (1989) sample were all students and this could have biased the pattern of results.

5.6.1 The influence of modality profiles and preferences on the use of social support coping strategies

Another reason for social support not being one of the most frequently used coping strategies was its relationship with two modalities, Affect and Interpersonal. Both modalities were correlated with and predicted a person's use of seeking emotional social support, but they were not related with each other. This suggests that people had different motives for using this strategy. People with a strong preference for Affect were also more likely to score higher on levels of anxiety. It could be that they use social support more as a way of seeking reassurance and lowering their level of anxiety. People who showed more Interpersonal tendencies were not found to be particularly anxious, but were also more inclined to use emotional social support.

To summarise, two different types of people are using the same strategy to cope with a particular problem, but one is more emotion orientated and the other is more people focused. This is not to suggest that emotional and interpersonal tendencies are exclusive of each other, but rather that preferences in a particular modality could effect the quality of interaction and people's experience of social support. Costa, et al (1996), made this point when arguing for the value of personality in coping research. They used the example of two people appearing to be similar in their use of a particular coping strategy, such as emotion focused ways of coping, but one person might use positive thinking and another self blame. Both would be categorised as emotional ways of coping, but the two approaches would have very different effects on a person's mood.

Another way to understand this finding would be to look at other variables associated with the aforementioned modalities. The Interpersonal modality was found to be related to Drugs and Health, and Affect was related to Sensation. A health conscious sociable person conjures up quite a different image from that of a person who is more focused on their emotional and sensory experiences. Affect was also associated with two other coping strategies, focusing on emotions and mental disengagement, which were associated with higher levels of anxiety. This provides further indication that there might be differences in reasons for seeking social support and the quality of the social interaction.

Some of the interactive relationships between modalities and coping strategies were quite complex. Seeking social support was related to Affect and Sensation, but instrumental social support also had a Cognitive component to it and emotional social support had an Interpersonal component. These differences are well illustrated in comments from the

interviews. Some people spoke about the benefits of emotional support from other amputees and others mentioned more instrumental support such as being more informed about types of limbs and services.

5.7 The importance of a sense of control in treatment

Although instrumental social support was not in itself one of the most used coping strategies, it was related to the more popular strategies of active coping, planning and acceptance. Interview data showed that actively seeking and sharing knowledge and information about services was very important to some people. It is possible that this kind of coping makes people feel more in control of their treatment rather than in a position of simply receiving services. A good example of this was one person's comment about his expectation that his legs should be made for him to lead his life, but he should not have to lead his life for his legs. He did not want the legs to stop him leading an ordinary life. Limiting his lifestyle according to the limitations of artificial limbs was not an option. He was quite proactive in his approach to treatment and would ask about any new developments in the technology.

There is evidence to suggest that a greater sense of controllability over a difficult situation has an effect on a person's mood and behaviour. One study (Reichert and Perrez, 1992) found that the more a person perceived a situation to be controllable, the more likely they were to try and seek further information about it. Aldwin (1996) also cites two studies (Mattlin, Wethington, and Kessler, 1990; Vitaliano, DeWolfe, Maiuro, Russo, and Katon, 1990) that found that in situations perceived to be controllable, problem focused coping is more effective in decreasing psychological symptoms, while in situations seen as uncontrollable,

emotion-focused coping is a better strategy for lowering symptom levels (Aldwin, 1996, p.153).

5.7.1 The differences between new and older amputees in perceptions of control over treatment

Perceptions of control over a distressing event were not measured in this study, but some people's comments during the interviews showed that they valued having a sense of control over their treatment and were keen for other people with an amputation to exert more control over treatment by asking more questions about the services available to them. More recent amputees were particularly seen as having little influence on their treatment. If, however, more recent amputees, and some older amputees for that matter, feel like they have little control over their situation then the above studies suggest that a problem-focused and information seeking approach might not be the best thing for them at that particular moment in time.

With regards to the type of situation where people perceive events as uncontrollable, there was some evidence to suggest that some participants did feel that way. There were some people who believed that they could get more from the service if they tried, but didn't, and subsequently felt that they accepted less quality than other patients. Practical issues were given as reasons for not trying. They felt it would involve more visits and waiting time at the fitting centre. For these people, time spent at the fitting centre was not always a positive experience, but instead could be quite a negative and distressing event. One person said that they only felt bad about their disability or even felt disabled when they were at the centre, because without her leg she could not get around and move out of her chair or even go to the

toilet herself. Crutches and wheelchairs were not routinely made available for people to stay mobile and independent during their appointment.

5.8 Users access to and knowledge of services for people with amputation.

Some amputees who knew about and had asked for the latest technology saw the fitting centre as a way of accessing new treatments. Indirectly, it facilitated a greater sense of mobility and independence because of the quality of the newer types of limbs. However, other people who had negative experiences of the service were less likely to ask for or press for the latest treatment and settled for maintaining their functional independence with the limbs that they already had. This was particularly noticeable in remarks about the quality of limbs. One person felt that the cosmetic finishes were very poor, but another had spoken about getting a new leg with a number of cosmetic features on it (this was not reported in the content analysis of interviews because the actual transcript did not fit with the categories and could also have identified the person).

On the whole though, people were not critical of the service and did not blame the people working there, they accepted that they were under a lot of pressure. Moreover, it seemed that they wanted greater equality in treatment and for appointments to be made less distressing by providing equipment that would allow people to stay active and mobile while they were there. Previous research has not looked at the differences in people's experiences of treatment or services. The present findings suggest that this would be an interesting and informative area of investigation. It might highlight differences in treatment between different countries. Most of the larger studies on adjustment to amputation have been carried out in the U.S which has a very different system of health care from the U.K.

5.9 The limitations of research findings in generalising to the wider population

5.9.1 Sociodemographic profile of the sample

As with any study there are limitations with the current research findings. As already mentioned, the number of female respondents in this sample was quite low, though as a percentage it was not unrepresentative of the wider population of people with amputation, who are predominantly male.

On the whole, the sample of respondents were quite physically able and reported relatively few functional disabilities. Their overall scores on the Functional Limitations Index were quite low. This might not be particularly representative of amputees as a whole, as some people can be much more limited. As a group, the sample might have been more able because most of the participants were recruited from the limb fitting centre. It therefore, excluded amputees who did not use a prosthesis or regularly visited the fitting centre. Pell et al (1993) found that among an older group of amputees (median age 73 years) only thirty-three percent could walk with a prosthesis outside their home and thirty-seven percent around their home. The fact that the majority of respondents in this study were recruited from a limb fitting centre showed that they used their prosthesis and were not wheelchair users.

5.9.2 Small sample size

The total sample size was also quite small and not every respondent managed to complete all of the questionnaires. Consequently some of the results are based on a smaller sample of 37 participants. With smaller sample sizes there is always the possibility that significant effects could disappear if the number of participants was increased. However, to guard against this

results were only reported as significant if they reached the more stringent 0.01 level of significance. This also offers some protection against Type 1 errors of accepting a hypothesis in error. Had the researcher been given more time it might have been possible to have recruited more volunteers.

5.9.3 Recruitment bias

A potential criticism of this study is the representativeness of the sample with regards to where they lived. Only one recruitment centre was used. There are well publicised differences in health and social services across the country. The amenities provided by local authorities are also likely to differ across the country and studies carried out elsewhere might find very different results because of this. Even in the present study there were some discrepancies in the type of support people were offered from social services with regards to home-help and practical aids for everyday living. The level of practical support that a person receives, especially with regards to maintaining levels of functional independence, could have a direct or indirect effect on their psychological health. One participant also mentioned the sense of exclusion from activities for amputees because of age limits. A sample that included more older respondents might produce a very different pattern of results if there are issues of exclusion or ageism.

5.10 Methodological Weaknesses

5.10.1 Hospital Anxiety and Depression Scale

One of the first potential weaknesses of this research are the measures that respondents were asked to complete. Previous studies have found higher numbers of participants reporting

symptoms of depression, however the current study did not find this. It is possible that the Hospital Anxiety and Depression Scale was not as sensitive as other measures that have been used, but research on the scale has shown it to be as good or better than some other measures (see Bowling, 1997). Therefore, it could be that other methodological variables such as recruitment procedures and small sample size meant that higher rate of depression amongst the sample were not detected. If this is the case, it could still be seen as a good thing for the services and staff that were involved in the care and treatment of amputees that no one in this sample indicated high levels of depressive symptomatology. Even the five participants who had just recently lost their limb scored low on the depression scale.

5.10.2 Recruitment bias

Regarding the recruitment procedures, it is possible that biases were operating in the selection procedures. A large number of participants who took part in the research were patients of one particular prosthesis. For reasons of minimal disturbance to the routine running of the service it was recommended that the researcher work with one prosthetist, who would ask their patients if they were willing to take part in the research. It is possible that more depressed patients were filtered out at this stage because of sensitivity to their current mood or that they themselves opted out of taking part. This also applies to in-patients on the rehabilitation programme, more depressed people might not have wanted to take part. Comments from interviews showed most of the patients of the prothetist to be very happy about the service they were receiving. As a general rule, when critical comments were made they were made in reference to other prosthetists people had had in the past.

5.10.3. Life Satisfaction Index

The Life Satisfaction Index showed more discriminatory power. It is an older test but still widely used in clinical settings. It has mainly been used with older adults, but some studies have also shown its value with younger respondents (George and Bearon, 1980). Some of the younger participants in this study felt that some items were not really relevant to them because they were still quite young, for example 'These are the best years of my life' or 'When I think over my life I didn't get most of the important things I wanted'. If these items seemed inappropriate to younger people might have responded by ticking the 'Don't know' answer and scored less on the overall life satisfaction scale. If this did happen it did not have a large effect on the results because there were no significant age differences on the Life Satisfaction Index. Still, it might have been better if a more ageless questionnaire had been used instead to measure life satisfaction.

The results from this measure might also have been more informative had it been possible to divide the index into its component dimensions (zest and apathy, resolution and fortitude, congruence between desired and achieved goals, positive self-concept and mood tone), but the scoring procedures only indicate how to calculate a total score and do not report which items are related to which dimension. The combining of scores for each dimension is a major criticism of the scale (Bowling, 1997).

5.10.4. COPE

On a practical note one of the criticisms that participants made about the COPE was that it was too long and repetitive. The measure consisted of sixty questions and some scales were more obviously repeated than others. Respondents were particularly critical of the repetition for two

of the scales, religion and drugs and alcohol. They felt that once they had indicated that these were not strategies that they usually used it was not necessary to be asked three more times. Another practical criticism of the design of the scale is that there is no repetition of the rating scale on the second page and respondent's often had to keep looking back to see how to rate their answers to the questions. This was easier when the researcher went through the questionnaires with participants because they had the rating scale in front of them while the researcher read out the questions.

Of course the scope of this study is very much limited to the responses of individual amputees, there is no way of knowing whether their assessment of themselves would be supported by their significant others. If the opinions of close friends and relatives, had been sought a very different picture might have emerged. This is one of the criticisms made of questionnaires like the COPE, that they are too introspective and are not used in comparison with other more objective measures that assess the reliability of individual answers (Marks, Murray, Evans, and Willig, 2000). For example, the subscale, denial, is criticised on the grounds that it is not a fully conscious process, so how would someone recognise that they did it? (ibid.).

This is quite a weak criticism if one takes a look at people's responses to items on the subscale. If it was a strategy that people did not recognise in themselves then one would not expect anyone to score on the subscale or for it to relate to other scales, but the present study and other research has found that the use of denial is related to higher scores on measures of distress. Anyhow, the main focus of this research study was to investigate intra-psychic processes and found out if and how they related to one another, not to look at how reliable

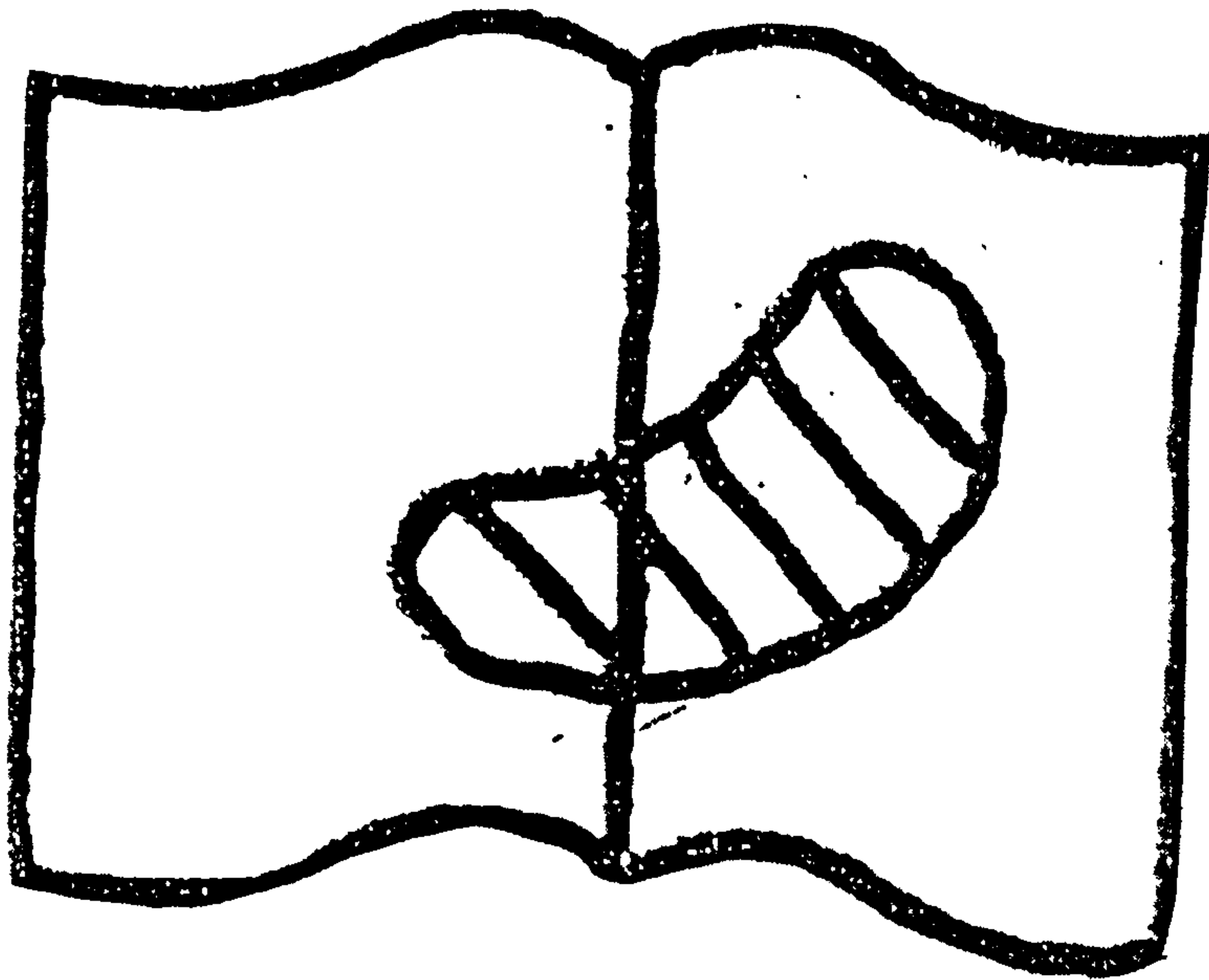
people's perceptions of themselves were. Carrying out a comparison between the responses of individual respondents and their significant others is quite a different type of investigation, one that could follow on from the present research to take the investigation a step further.

With regards to the analyses of responses from the COPE, this research could be criticised for not grouping the subscales together and making the results more concise. Previous studies, such as Livneh et al (1999) grouped responses into dimensions such as problem solving and emotion coping, as suggested by the questionnaire's authors Carver et al (1989). Schwarzer and Schwarzer (1996) suggest that the evidence for doing this is quite weak because a second order factor analysis carried out to confirm the two-dimensional structure of the questionnaire did not replicate the structure (Carver, et al., 1989; Zeidner and Hammer, 1992).

There are shorter measures of coping, but the COPE was used because it is quite a well used research instrument and easily available to the researcher (it was part of a Health Measures package owned by the training scheme, which once purchased, did not require users to seek permission to use or photocopy the questionnaires as long as they were part of the training scheme). The researcher wanted to use well established measures alongside the Structural Profile Inventory because it is a measure rarely used in research, let alone with a sample of amputees. The COPE has previously been used in research with amputees (Livneh, et al, 1999).

The dispositional version of the questionnaire was used instead of the situational version because if amputation had been chosen as the specific situation the responses of older amputees would be based more on retrospective memory compared with more recent

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amputees. There is are also problems with using the dispositional version though, in that more newer amputees might have thought about their amputation as a recent stressful experience more than older amputees. Though, comments made during the interviews suggested that older amputees also thought about ways that they coped with amputation especially if they had had recent health problems such as an infection in their stump that had effected their walking.

5.10.5 Structural Profile Inventory

This was a relatively easy to administer and quick questionnaire. The only statement which respondents seemed to find difficult was a double negative item 'I would not be described as a loner'. Some people found this difficult to answer because if they agreed with the statement it sounded like one was agreeing to being a loner. As with the COPE, the SPI is very introspective and there is no way of knowing from the current study whether other people close to the participants would agree with their assessment of themselves. Even without including significant others, it might have been possible to have cross-checked the consistency of people's responses by using other questionnaires that looked at similar issues such as social support, health promotion behaviours, and daily activity levels. This would however, of taken a long time for people to complete and they might have been less willing to participate.

5.10.6 Qualitative methodology and analysis

It was unfortunate that variations in levels of privacy meant that not all respondents were able to be interviewed. Despite this the majority of participants (72.5 %) did take part in interviews. Most people found it fairly easy to talk about what they had found helpful and were particularly praising of the nursing care that they had received. Some participants appeared to

find it more difficult to think of anything that they found unhelpful and further prompting was often required (e.g. could anything be better, changed or improved). The question might have been too vague and difficult to answer, especially for people whose amputation had been several years ago. It could also have been experienced as quite a separate part of the research. The questionnaires largely focused on people's own perception of themselves, whereas the interview questions were asking people to talk about their perception of others. Some respondents might have been more hesitant than others about saying anything too critical in case it effected their treatment. All participants were assured of the anonymity and confidentiality of their responses, but for many people the experience of having their opinions recorded on tape is not a familiar one and this might have made it more difficult for them to talk about negative aspects of their care.

The analysis of interview transcripts is vulnerable to errors because of the subjectivity of interpretation. To guard against this an inter-rater reliability check was carried out to limit the potential for bias. This does not mean that another researcher would necessarily come up with the same themes if they were to analyse the interview data, but that there is a reasonable level of agreement between raters to suggest that the themes were representative of particular units of text. The inter-rater reliability check in this study was quite favourable and showed a high level of agreement.

Unfortunately, this study did not include member validation. Member validation involves a researcher taking the analysis of interviews back to the participants so that they can check or comment on the interpretation (Smith, 1998). Time limitations and practical constraints would have made it very difficult to carry out this kind of validation. Up to twenty-nine participants

would have had to of been re-contacted by letter and arrangements made to talk about the results. This would have involved a great deal of time, organisation, and travel, which was just not possible. Participants will however, be sent a summary sheet outlining the main findings of the research if they requested such on their consent form.

Qualitative methodology is usually criticised for producing results that are specific to the participants of each particular study and not necessarily generalisable or representative of the wider population. This is a fair comment, but in this study findings from the qualitative results supported some of the quantitative data and provided good examples with which to illustrate the quantitative results. It highlighted the issue of perceptions of controllability and their relationship to coping strategies. This was something that had not been considered in the research questions, nor had it been included in previous research looking at adjustment to amputation.

5.11 Service Implications

In conclusion, overall the results from interviews show that people are relatively satisfied with the services that they receive. There were favourable reports about nursing care at the time of amputation and the after care from physiotherapists and other professionals involved in rehabilitation. There were two main areas that people felt there could be changes in and improvements made. The first was regarding the issue of maintaining a sense of mobility during long appointments at the fitting centre. Rather than sitting around and waiting for the prosthetist to work on their limbs, some patients wanted to be able to move about within the centre. It is uncertain how practical this would be, but as one person remarked, it would just be nice to be able to go to the toilet if they needed without asking someone for a pair of crutches.

The second issue was about making information more available. This included publicising any new advances in technology that were related to prostheses and informing people, particularly older amputees, about community support services available. One person suggested that there could be more posters and notices of information put up on the walls of fitting rooms. People felt that older and more recent amputees were particularly disadvantaged because they were often uninformed and unaware of the range of services available. Having greater access to information can be beneficial for people adjusting to recent amputation, as well as longer-term amputees experiencing difficulties related to amputation.

5.12 Implications for clinical psychology

Current findings suggest that issues of adjustment for people with amputation are complicated and multifaceted. More recent amputees are generally less satisfied with life, but longer term amputees can also be less satisfied if they have had recent physical health problems related to their amputation. This supports Fitzpatrick's (1999) assertion that adaptation and adjustment to amputation is a life-long process that has highs and lows. Therefore, psychologists and clinicians should be aware that even people who have coped very well for several years with amputation could also be at risk of developing depression.

The value of reinterpreting problems in a positive way has already been well researched and is incorporated into psychological therapies (e.g. cognitive behavioural therapy). What has not been as thoroughly investigated, is the relationship between personality variables and preference towards certain coping strategies. Results from this study suggest that people who are more behaviour and cognitive orientated are more likely to use a range of problem-focused coping strategies. Whereas, people more focused on emotions and sensations are more likely

to use coping strategies associated with higher levels of distress. In therapy, the goal of clinical psychologist and client could be to understand how such strategies, thoughts and behaviour, effect mood and consider the value of using other ways of coping with difficult situations.

The language of this might appear to be very characteristic of cognitive behavioural therapy, but the general underlying theme is similar for most therapies. Very simply, most therapeutic approaches aim to help clients make more sense of their situation, understand how past or current issues and events relate to their emotional state, and consider how they could use this knowledge about themselves to help alleviate symptoms of distress. The results of this research simply suggest that one approach which might prove useful in helping people to learn coping strategies more associated with well-being is Multimodal therapy. This is where the present study differs from previous research looking at coping strategies and amputation. It is not simply looking at the types of coping strategies used by people with amputation and relating them to adjustment and adaptation. Moreover, it is taking the research one step further in suggesting that there are certain personality modalities associated with the use of particular coping strategies and that change might need to happen at the level of modality preferences before a person is willing to use alternative coping strategies.

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Instructions for the self-administered FLP questionnaire

Introduction to the respondent

We are interested in the activities that you do in carrying on your life and any changes that describe you today that are related to your health.

This questionnaire lists statements that describe things people often do when they are not well. Even if you think you are well, some of these statements may stand out, because they describe you and are related to your health.

As you read each statement in the questionnaire, think of yourself today. When you read a statement that describes you and is related to your health, place a tick in the box to the right of the statement.

For example if you have not been driving for some time because of your health and are still not driving today, you should tick the following statement:

I am not driving my car

☐

On the other hand, if you never drive or are not driving today because your car is being repaired, you should **not** tick it. Tick a statement **only** if you are **sure** it describes you and is due to health.

Note: At the bottom of each page of the self-administered questionnaire, you should indicate that you have read all the statements on the page by ticking the following statement:

TICK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE

☐

FUNCTIONAL LIMITATIONS PROFILE



Name:.....

Date:..... Record Number:.....

Ambulation items (maximum possible score = 1,006)

The following statements describe walking and use of stairs. Remember, think of yourself today. Only tick the box if you agree with the statement, and if it is due to the state of your health.

		Item weight
1. I walk shorter distances or often stop for a rest.	<input type="checkbox"/>	(54)
2. I do not walk up or down hills.	<input type="checkbox"/>	(64)
3. I only use stairs with a physical aid; for example, a handrail, stick or crutches.	<input type="checkbox"/>	(82)
4. I only go up and down stairs with assistance from somebody else.	<input type="checkbox"/>	(87)
5. I get about in a wheelchair.	<input type="checkbox"/>	(121)
6. I do not walk at all.	<input type="checkbox"/>	(126)
7. I walk by myself but with some difficulty; for example, I limp, wobble, stumble or I have a stiff leg.	<input type="checkbox"/>	(71)
8. I only walk with help from somebody else.	<input type="checkbox"/>	(98)
9. I go up and down stairs more slowly; for example, one step at a time or I often have to stop.	<input type="checkbox"/>	(62)
10. I do not use stairs at all.	<input type="checkbox"/>	(106)
11. I get about only by using a walking frame, crutches, stick, walls, or hold on to furniture.	<input type="checkbox"/>	(96)
12. I walk more slowly.	<input type="checkbox"/>	(39)

TICK HERE WHEN YOU HAVE READ ALL THE STATEMENTS ON THIS PAGE ☐



Body care and movement items (maximum possible score = 1,927)

The following statements describe how you move about, bath, go to the toilet, dress yourself **today**. Only tick the box if you agree with the statement, and it is due to the state of your health.

		Item weight
13. I make difficult movements with help; for example getting in or out of the bath or car.	<input type="checkbox"/>	(82)
14. I do not get in and out of bed or chairs without the help of a person or mechanical aid.	<input type="checkbox"/>	(100)
15. I only stand for short periods of time.	<input type="checkbox"/>	(67)
16. I do not keep my balance.	<input type="checkbox"/>	(93)
17. I move my hands or fingers with some difficulty or limitation.	<input type="checkbox"/>	(66)
18. I only stand up with someone's help.	<input type="checkbox"/>	(93)
19. I kneel, stoop or bend down only by holding on to something.	<input type="checkbox"/>	(61)
20. I am in a restricted position all the time.	<input type="checkbox"/>	(124)
21. I am very clumsy.	<input type="checkbox"/>	(47)
22. I get in or out of bed or chairs by grasping something for support or by using a stick or a walking frame.	<input type="checkbox"/>	(79)
23. I stay lying down most of the time.	<input type="checkbox"/>	(120)
24. I change position frequently.	<input type="checkbox"/>	(513)
25. I hold on to something to move myself around in bed.	<input type="checkbox"/>	(82)
26. I do not bathe myself completely; for example I need help with bathing.	<input type="checkbox"/>	(85)
27. I do not bathe myself at all, but am bathed by someone else.	<input type="checkbox"/>	(100)
28. I use a bedpan with help.	<input type="checkbox"/>	(107)
29. I have trouble putting on my shoes, socks or stockings.	<input type="checkbox"/>	(54)
30. I do not have control of my bladder.	<input type="checkbox"/>	(122)
31. I do not fasten my clothing; for example I require assistance with buttons, zips or shoelaces.	<input type="checkbox"/>	(68)
32. I spend most of the time partly dressed or in pyjamas.	<input type="checkbox"/>	(75)
33. I do not have control of my bowels.	<input type="checkbox"/>	(124)
34. I dress myself, but do so very slowly.	<input type="checkbox"/>	(43)
35. I only get dressed with someone's help.	<input type="checkbox"/>	(82)

TICK HERE WHEN YOU HAVE READ ALL THE STATEMENTS ON THIS PAGE

☐


Mobility items (maximum possible score = 727)

These next statements describe how you get about the house and outside. Only tick the box if you agree with the statement, and it is due to the state of your health.

	Item weight
36. I only get about in one building.	<input type="checkbox"/> (76)
37. I stay in one room.	<input type="checkbox"/> (101)
38. I stay in bed more.	<input type="checkbox"/> (91)
39. I stay in bed most of the time.	<input type="checkbox"/> (114)
40. I do not use public transport now.	<input type="checkbox"/> (52)
41. I stay at home most of the time.	<input type="checkbox"/> (79)
42. I only go out if there is a lavatory nearby.	<input type="checkbox"/> (64)
43. I do not go into town.	<input type="checkbox"/> (47)
44. I only stay away from home for short periods.	<input type="checkbox"/> (46)
45. I do not get about in the dark or in places that are not lit unless I have someone to help.	<input type="checkbox"/> (57)

Household management items (maximum possible score = 695)

The following statements describe your daily work, around the home. When you answer, think of yourself today. Only tick the box if you agree with the statement, and it is due to the state of your health.

	Item weight
46. I only do housework or work around the house for short periods of time or I rest often.	<input type="checkbox"/> (50)
47. I do less of the daily household chores than I would usually do.	<input type="checkbox"/> (37)
48. I do not do any of the daily household chores that I would usually do.	<input type="checkbox"/> (90)
49. I do not do any of the maintenance or repair work that I would usually do in my garden.	<input type="checkbox"/> (75)
50. I do not do any of the shopping that I would usually do.	<input type="checkbox"/> (84)
51. I do not do any of the cleaning that I would usually do.	<input type="checkbox"/> (78)
52. I have difficulty using my hands; for example, turning taps, using kitchen gadgets, sewing or doing repairs.	<input type="checkbox"/> (78)
53. I do not do any of the clothes washing that I would usually do.	<input type="checkbox"/> (75)
54. I do not do heavy work around the house.	<input type="checkbox"/> (59)
55. I have given up taking care of personal or household business affairs; for example, paying bills, banking or doing household accounts.	<input type="checkbox"/> (69)

TICK HERE WHEN YOU HAVE READ ALL THE STATEMENTS ON THIS PAGE

☐


Structural Profile Inventory

In the space next to each of the following items, please write down the number that most accurately reflects your opinion.

Strongly Disagree	Moderately Disagree	Slightly Disagree	Neutral	Slightly Agree	Moderately Agree	Strongly Agree
1	2	3	4	5	6	7

Number: _____ Date: _____

- 1. _____ I tend to plan things and think about them a great deal.
- 2. _____ I often imagine situations in pictures.
- 3. _____ In making a decision, I often let my feelings and emotions determine what I should do.
- 4. _____ Basically, I'm in excellent health.
- 5. _____ I can form clear mental pictures.
- 6. _____ I get sufficient rest and relaxation.
- 7. _____ I would probably be described as "active and energetic".
- 8. _____ I would *not* be described as a "loner".
- 9. _____ I am a very active person.
- 10. _____ I am a "people person".
- 11. _____ I follow good nutritional habits.
- 12. _____ Most of the time, I'd rather be with other people than alone.
- 13. _____ I often engage in intellectual (cognitive) activities.
- 14. _____ I can form vivid pictures in my imagination.
- 15. _____ I avoid overeating, too much alcohol, and keep away from harmful things such as drugs and tobacco.
- 16. _____ I am tuned into my senses, what I see, hear, taste, smell, and touch.
- 17. _____ Friendships are very important to me.
- 18. _____ I consider myself sensual and sexual.
- 19. _____ I usually think before acting.
- 20. _____ I am aware of the ways in which my senses react to different stimuli.
- 21. _____ I am an imaginative person.
- 22. _____ I have very deep feelings and emotions.
- 23. _____ I reason most things out quite thoroughly.
- 24. _____ I keep busy doing things.
- 25. _____ I think more in pictures than in words.
- 26. _____ I take good care of my body.
- 27. _____ I keep occupied and on the go.
- 28. _____ I pay a lot of attention to my feelings and emotions.
- 29. _____ I have several close or intimate friendships.
- 30. _____ I focus a great deal on my bodily sensations.
- 31. _____ I am a very emotional person.
- 32. _____ I analyse things quite thoroughly.
- 33. _____ My feelings are easily aroused and /or changeable.
- 34. _____ I am full of pep and vigour.
- 35. _____ Most of my five senses are very keen (smelling, tasting, seeing, hearing, touching).

COPE

Name:

Date: **Record Number:**

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by choosing one number for each, using the response choices listed just below.

1 = I usually don't do this at all.

2 = I usually do this a little bit.

3 = I usually do this a medium amount.

4 = I usually do this a lot.

Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no 'right' or 'wrong' answers, so choose the most accurate answer for YOU – not what you think 'most people' would say or do. Indicate what YOU usually do when YOU experience a stressful event.

1. I try to grow as a person as a result of the experience.
2. I turn to work or other substitute activities to take my mind off things.
3. I get upset and let my emotions out.
4. I try to get advice from someone about what to do.
5. I concentrate my efforts on doing something about it.
6. I say to myself "this isn't real".
7. I put my trust in God.
8. I laugh about the situation.
9. I admit to myself that I can't deal with it, and give up trying.
10. I restrain myself from doing anything too quickly.
11. I discuss my feelings with someone.
12. I use alcohol or drugs to make myself feel better.
13. I get used to the idea that it happened.
14. I talk to someone to find out more about the situation.
15. I keep myself from getting distracted by other thoughts or activities.
16. I daydream about things other than this.
17. I get upset, and am really aware of it.
18. I seek God's help.
19. I make a plan of action.
20. I make jokes about it.

[illegible]

- | | |
|---|--------------------------|
| 21. I accept that this has happened and that it can't be changed. | <input type="checkbox"/> |
| 22. I hold off doing anything about it until the situation permits. | <input type="checkbox"/> |
| 23. I try to get emotional support from friends and relatives. | <input type="checkbox"/> |
| 24. I just give up trying to reach my goal. | <input type="checkbox"/> |
| 25. I take additional action to try to get rid of the problem. | <input type="checkbox"/> |
| 26. I try to lose myself for a while by drinking alcohol or taking drugs. | <input type="checkbox"/> |
| 27. I refuse to believe that it has happened. | <input type="checkbox"/> |
| 28. I let my feelings out. | <input type="checkbox"/> |
| 29. I try to see it in a different light, to make it seem more positive. | <input type="checkbox"/> |
| 30. I talk to someone who could do something concrete about the problem. | <input type="checkbox"/> |
| | |
| 31. I sleep more than usual. | <input type="checkbox"/> |
| 32. I try to come up with a strategy about what to do. | <input type="checkbox"/> |
| 33. I focus on dealing with this problem and, if necessary, let other things slide a little. | <input type="checkbox"/> |
| 34. I get sympathy and understanding from someone. | <input type="checkbox"/> |
| 35. I drink alcohol or take drugs, in order to think about it less. | <input type="checkbox"/> |
| 36. I kid around about it. | <input type="checkbox"/> |
| 37. I give up the attempt to get what I want. | <input type="checkbox"/> |
| 38. I look for something good in what is happening. | <input type="checkbox"/> |
| 39. I think about how I might best handle the problem. | <input type="checkbox"/> |
| 40. I pretend that it hasn't really happened. | <input type="checkbox"/> |
| | |
| 41. I make sure not to make matters worse by acting too soon. | <input type="checkbox"/> |
| 42. I try hard to prevent other things from interfering with my efforts at dealing with this. | <input type="checkbox"/> |
| 43. I go to the cinema or watch television, to think about it less. | <input type="checkbox"/> |
| 44. I accept the reality of the fact that it happened. | <input type="checkbox"/> |
| 45. I ask people who have had similar experiences what they did. | <input type="checkbox"/> |
| 46. I feel a lot of emotional distress and I find myself expressing those feelings a lot. | <input type="checkbox"/> |
| 47. I take direct action to get around the problem. | <input type="checkbox"/> |
| 48. I try to find comfort in my religion. | <input type="checkbox"/> |
| 49. I force myself to wait for the right time to do something. | <input type="checkbox"/> |
| 50. I make fun of the situation. | <input type="checkbox"/> |
| | |
| 51. I reduce the amount of effort I'm putting into solving the problem. | <input type="checkbox"/> |
| 52. I talk to someone about how I feel. | <input type="checkbox"/> |
| 53. I use alcohol or drugs to help me get through it. | <input type="checkbox"/> |
| 54. I learn to live with it. | <input type="checkbox"/> |
| 55. I put aside other activities in order to concentrate on this. | <input type="checkbox"/> |
| 56. I think hard about what steps to take. | <input type="checkbox"/> |
| 57. I act as though it hasn't even happened. | <input type="checkbox"/> |
| 58. I do what has to be done, one step at a time. | <input type="checkbox"/> |
| 59. I learn something from the experience. | <input type="checkbox"/> |
| 60. I pray more than usual. | <input type="checkbox"/> |

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Name:

Date:

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or 'wound up':

- Most of the time
A lot of the time
Time to time, Occasionally
Not at all

I feel as if I am slowed down:

- Nearly all the time
Very often
Sometimes
Not at all

I still enjoy the things I used to enjoy:

- Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all
Occasionally
Quite often
Very often

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

I have lost interest in my appearance:

- Definitely
I don't take so much care as I should.....
I may not take quite as much care
I take just as much care as ever

I can laugh and see the funny side of things:

- As much as I always could
Not quite so much now
Definitely not so much now
Not at all

I feel restless as if I have to be on the move:

- Very much indeed
Quite a lot
Not very much
Not at all

Worrying thoughts go through my mind:

- A great deal of the time
A lot of the time
From time to time but not too often...
Only occasionally

I look forward with enjoyment to things:

- As much as ever I did
Rather less than I used to
Definitely less than I used to
Hardly at all

I feel cheerful:

- Not at all
Not often
Sometimes
Most of the time

I get sudden feelings of panic:

- Very often indeed
Quite often
Not very often
Not at all

I can sit at ease and feel relaxed:

- Definitely
Usually
Not often
Not at all

I can enjoy a good book or radio or TV programme:

- Often
Sometimes
Not often
Very seldom

Life Satisfaction Index (LSI)

Here are some statements about life in general that people feel differently about. Would you read each statement in the list, and if you agree with it put a tick in the space under 'agree'. If you do not agree with the statement, put a tick in the space under 'disagree'. If you are not sure one way or the other, put a tick under '?'. *Please be sure to answer every question on the list.*

Agree	Disagree	?	
___	___	___	As I grow older, things seem better than I thought they would be.
___	___	___	I have had more of the breaks in life than most of the people I know.
___	___	___	This is the dreariest time of my life.
___	___	___	I am just as happy as when I was younger.
___	___	___	My life could be happier than it is now.
___	___	___	These are the best years of my life.
___	___	___	Most of the things I do are boring or monotonous.
___	___	___	I expect some interesting or pleasant things to happen to me in the future.
___	___	___	The things I do are as interesting to me as they ever were.
___	___	___	I feel old and somewhat tired.
___	___	___	I feel my age, but it does not bother me.
___	___	___	As I look back on my life, I am fairly well satisfied.
___	___	___	I would not change my past even if I could.
___	___	___	Compared to other people my age, I've made a lot of foolish decisions in my life.
___	___	___	Compared to other people my age, I have a good appearance.
___	___	___	I have made plans for things I'll be doing a month or a year from now.
___	___	___	When I think back over my life, I didn't get most of the important things I wanted.
___	___	___	Compared to other people, I get down in the dumps too often.
___	___	___	I've got pretty much what I expected out of life.
___	___	___	In spite of what people say, the lot of the average person is getting worse, not better.

CONSENT FORM

Please fill out this form only if you wish to take part in the study. Your name and address are only needed so that a meeting can be arranged with you after your appointment at the clinic. Once the date and time of the meeting has been arranged these details will be destroyed and you will only be identified as a numbered participant.

I give my consent to take part in a research study about psychological adjustment to amputation. I understand that any information I give in this study will be kept confidential and my anonymity will be protected. I also understand that even though I consent to take part in this study I can change my mind at any time and without reason decide not to take part at a later date.

Signed:

Print Name:

Address:
.....
.....
.....

I would like a copy of the report summarising the results from the research (please tick box).

Yes ☐

No ☐

A STUDY INVESTIGATING PSYCHOLOGICAL ADJUSTMENT TO AMPUTATION

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything that is not clear or if you would like more information please contact me at the address given below. Take time to decide if you wish to take part or not.

Purpose of the study:

I am a Clinical Psychologist in training. As part of my training I must carry out some research in my final year and write a dissertation about it. The research is about psychological adjustment to amputation. I am interested to find out how people differ in the way they cope with amputation and how they adjust to the changes that this brings to their life. It is hoped that the information gained from this study could be used to help health services provide better care for people who have had an amputation.

Why have you been chosen?

You will have been given this information sheet because you are attending an appointment at the amputation clinic. Other patients with appointments over the next few months will also been given a copy of this information sheet during their visit to the centre.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide you will be given a consent form to sign. If you do decide to take part you are still free to withdraw at any time and without giving reason. This will not effect the standard of care you receive.

What will happen if I take part?

Taking part means meeting with me at the clinic in a private room before or after your appointment. You will be asked to fill out some questionnaires and to give your comments about the care you have received from healthcare staff since your amputation. The meeting should take between 25 and 40 minutes. The information you give in the questionnaires will be anonymous and be treated as confidential. Your comments about the care you have received from hospital staff will be tape recorded. These recordings will be anonymous and not shared with anyone. They will only available to the researcher to analyse at a later date and will be destroyed once the research is completed.

What will happen to the results of the research study?

The results of the study will be reported on in my dissertation for the clinical psychology training course. I will also prepare a short report summarising the results. This will be made available to people who took part and staff at the hospital where the research was carried out. If you would like a copy of this sent to you please indicate on the consent form.

Who has reviewed the study?

NHS Trust,
Research Ethics Committee.

Contact for further information

-

Clinical Psychologist in Training
Clinical Psychology Training Course
Salomons: Canterbury Christ Church University College,
David Salomons Estate, Broomhill Road,
Southborough,
TUNBRIDGE WELLS
Kent TN3 0TG

Tel: 01892 507685 /6
E-mail:

Regression Tables

A) Modality predictors for Active Coping

	Beta	t	Significance
Behaviour	0.169	1.148	0.259
Cognition	0.499	3.504	0.001
Drugs and health	0.156	1.087	0.284

($R^2 = 0.44$, Adjusted $R^2 = 0.39$, $N = 38$).

B) Modality predictors for Seeking instrumental social support

	Beta	t	Significance
Affect	0.339	2.089	0.044
Sensation	0.114	0.652	0.519
Cognition	0.384	2.582	0.014

($R^2 = 0.38$, Adjusted $R^2 = 0.33$, $n = 37$).

C) Modality predictors for seeking emotional social support

	Beta	t	Significance
Affect	0.621	4.319	0.000
Sensation	0.068	0.453	0.653
Interpersonal	0.344	2.682	0.011

($R^2 = 0.51$, Adjusted $R^2 = 0.47$, $n = 37$).

D) Modality predictors for Suppression of Competing Activities

	Beta	t	Significance
Affect	0.305	1.777	0.085
Sensation	0.119	0.645	1.085
Cognition	0.328	2.082	0.045

($R^2 = 0.31$, Adjusted $R^2 = 0.25$, $n = 37$).

E) Modality predictors for Positive reinterpretation and growth

	Beta	t	Significance
Imagery	0.205	1.376	0.178
Behaviour	0.505	3.472	0.001
Cognition	0.098	0.658	0.515

($R^2 = 0.44$, Adjusted $R^2 = 0.39$, $n = 37$)

F) Modality and Coping style predictors for levels of Anxiety

	Beta	t	Significance
Focusing on and venting of emotions	0.506	2.508	0.018
Denial	0.051	0.292	0.773
Mental disengagement	0.177	1.127	0.268
Cognition	0.036	0.283	0.779
Affect	0.124	0.819	0.419

($R^2 = 0.55$, Adjusted $R^2 = 0.48$, $n = 37$).

G) Modality, Coping style and Physical limitation predictors for levels of Life satisfaction

	Beta	t	Significance
Positive reinterpretation	0.028	0.113	0.911
Mental Disengagement	0.280	1.869	0.071
Humour	0.341	1.631	0.113
Behaviour	0.177	0.986	0.332
Physical limitations	0.202	1.417	0.166

($R^2 = 0.46$, Adjusted $R^2 = 0.377$, $n = 38$).

Transcript Categories

1. Things that are helpful

a). Being with other amputees

“Possibly the only drawback with that was I wasn’t with other amputees, which I’ve found since helps a lot. Being with other people in the same situation, seeing that there are other people in the same situation”

“The things I found most helpful - I had a visit when I was in hospital, when I was first had the amputation. A guy come to visit who had a, his was below the knee, not above the knee, but it was a, that was one of the most helpful things - explain what I could expect”

“I’ve spoken to a couple of guys here, no one, they’re actually having fittings or whatever, no-one came to speak to them in the hospital. So basically that would be a real help because they think well I’ll never be able to ride push bike again, won’t be able to do this won’t be able to do that, you know”.

“And seeing other people in the same situation, I started to cool down and take the situation as it is. We try to encourage each other. Try to encourage each other to try , get up and do what you can” .

I came to, to a limb fitting centre there, which was very nice because all the people there were all amputees themselves... So that was brilliant because you could tell them, you could tell them exactly, even down to the phantom pain, you know and itching... They knew exactly what you were talking about. I think it was very very important. It was brilliant. And when you were, and when you had an ache or a pain on the limb and you said to them oh it’s catching me on the lower part of the knee he knew exactly what you were talking about, you know what I mean. I thought it made a marvellous difference.

b). Practical Help from professionals

“The social services they came and asked me what things I wanted for the toilet. I got bars put up for the toilet for me to reach the seat of the toilet. I got that and otherwise I got no help at all”

“An occupational therapist and a physiotherapist came and looked at the house before I came home to check that everything was all right for me to go there”

“The physios, yes that’s right. They were excellent, I must say... That was superb, I must say. I mean the girls, the physios down in the walking school are wonderful”.

“I mean the local services they even cut down a hedge, and made an entrance place by the side of the house onto the lawn so a car could be driven in and I could get into it. And I got, what have I got? A new wheelchair and they came round and for the first month I had somebody in, to see me, to get me up in the morning and bath and that sort of thing.”

“I’ve always been looked after by all the doctors and the fitters I had all the time I was a patient and I’m happy and pleased with what they’ve done. And every year it gets better and better. The technology’s got better over the years”.

“I find coming up to the walking school very helpful and very good, yes. They were always there when you wanted them” .

“They contacted me and asked if there’s anything they could do. In fact they sent some forms to fill in, can you go to the toilet in the middle of the night or do you have to have somebody to help you, are you this and that, and I put no to every one of them” .

B. Things that are unhelpful

a). Impact of fitting and repair time

“I’ve got a busy job. I know I’ve got to get back to work. I can’t afford to sit here all day. I’m sure I could get more, but I don’t have, you know a whole day to sit here because, and even if I say to work right I’m not gonna come back in I know after I’ve been here 2 or 3 hours my sort of stress levels are so high because of feeling totally unable to move around”.

“You come in to just have an alteration or final fitting and you be sitting in here for an hour and a half and then he’ll come and try it and he’ll say oh I’m just gonna make an adjustment, back in five minutes. I know it’s not their fault they’re busy with they’re buried in work and another hour goes by. And I’ve been here all day and basically had nothing done, you know”.

“the length of time it takes to get repairs done, new legs made, whatever, that that can make you feel quite disabled. I only ever feel bad about my disability when I’m here and that’s not necessarily the fault of the people who work here but just the actual environment”.

“I don’t mind coming here, apart from the time it takes... Yes, which sometimes if you’re reasonably busy you can’t always wait a week. So it’s ... That you can just pop in the following day and you know someone will always see you even if you have to wait for a while.”

“The only sort of complaints I would say is just the time it takes... That was the only gripe really, just the time it takes to get things fixed”.

“the problem is now that you have to keep coming back up every other week. The difficult thing is knowing that to fit an artificial leg with a patient if done correctly, done skilfully, if measured up and everything, you can produce that leg for that patient in a few days, and then the patient can then walk away. But there are some people who come up here trying to get their leg fixed for one, two three or five years. So it's more frustration than anything.

“I find pressures of the people here make it very difficult to feel anything less than very disabled when here because of the time it takes to do”

“So you accept less than you should because it takes so long to do anything”.

3. The experience of having an amputation and artificial limb

a). Access to services and passing on knowledge

“I've always had the best, feel as though I've always had the best. I'm quite an active person so I've sort of been useful, I like to think I've been useful for them because they've been able to experiment with different things on me. Different procedures they've been trying. It's been offered, People see that you're enthusiastic”.

“Like go to shop-ability sort of thing and so many things. Now I learnt all these little things from my next door neighbour. Now why should I have to learn from the next door neighbour? You see it's wrong. I know, a lot of things you can't ... They do a lot of good things, but just the same something could be...more information would be a big big thing, you know”.

“I'm lucky, cos I've said what's coming on. There's a new type of foot coming out which is fully adjustable which I've gone to the doctor and told him, I get on very well with him, I want to try it. Because it's me and we get on well he said yeah yeah yeah have a go. I don't think the average limbless person gets that opportunity they only learn what's on the market from what somebody else has got. I think a lot of disabled people are seen here. Cos predominantly they're older people aren't they? Predominantly they are, shall we say subservient to the people”.

“I suppose another criticism would be maybe not so much now but maybe in the past you don't, as a patient, you don't see what's available. Like if you go and buy a car you can go and look at all the different cars. When you come into this situation you look to the doctors and fitters and they tell you what you will have basically, they will say well this is available, this is the best and that's it. You don't have a, no showrooms, there are no showrooms, no catalogues, and it's not very often that a limbless person will be in contact with a lot of other limbless people to know, to network and what you know between yourselves”.

“Unfortunately, he who shouts the loudest gets the best and I'm, at my age I'm prepared to shout. And newer amputees don't, I feel sorry for them. I've even sat in here and I've,

when the prothetist's has gone out, in the past I've done it, I've said, you know, do you know you can get this done, do you know they've got that, "have they, I didn't know that", then I get out the room quick before they start asking. Cos it's the only way you're gonna find out isn't it."

"The only thing is you aren't told here, you're not told what's available. And you hear that from other people who've got... You see somebody whose in the waiting room or in one of these rooms, these fitting rooms and you say, Oh'll where's that come from, Oh'll you got it here like, oh you know. I mean I learnt, there was a woman here and she got a dancing leg, a skiing leg, you know".

"The problem is that the majority of amputees are sixty-five to eighty years old and they're just basically told to sit down and been quiet and go away, and if you're someone whose got a bit of common sense and won't take no for an answering and insists on things then that's where you come up against resistance".

"all right, you come here and you see different things you know, but a lot of them don't include you, do you know what I mean. You know, when you find out about them, oh no you're sixty-five you can't have it".

"And I do think things like cosmetic finishes are very poor, poorly designed and it means that, you know if you're never gonna wear, go bare legged or wear shorts it might not matter, but it does matter if you're fairly young and you want, you don't want to sort of stand out"

b). Emotional Aspects

"it's not just looking at a person and saying well mechanically they need this that and the other, it's a lot of emotional and things that should be take into consideration and the activities that the person is going to pursue is all very important and it takes time to build up that repertoire between patient and fitter"

"and it would be hard for the first few months even a year. Everyone's gonna, everyone feels the same, you get real despondent after the first year because nothing goes right basically. Or you think nothing's going right. The legs you know, you keep changing shape and the stump whatever, but first twelve months are the worst".

"Maybe more awareness of what the disabled person needs regarding confidence building. You know people experience horrific accidents for the person maybe who is looking on. But the actual subject themselves ... A counselling system ... I mean that's terribly important. I suspect perhaps now as opposed to the 1960's things moved on more in that direction. Looking back on it I can only tell you how I felt at the time"

"I was a bit stubborn though, a bit determined. I never ever stopped... to I think it gives you, it makes you determined to sort of like try and do well. And I think that's where I get my fighting spirit from... So I always tried in what I did".

“To actually come to terms with having the leg off more or less wasn’t a problem.”

“Well I think, you see when a person goes into hospital they have their leg taken away, they’re really having half their body taken away you know all the functional things. And a lot of people feel really hard done by you know”

“The fact that I’m sat here now and I’ve got no leg, no crutches or anything. If I want to go to the toilet or if I wanna do anything I’m completely trapped... it turns you from being very sort of independent and able to being disabled really, not having any say in what you can do or not do... but certainly I feel that it means that I don’t get the best care possible because I get very stressed about being here and I just wanna go”.

“I mean the other night somebody came round to our house at 1.30 in the morning... they were shouting outside so my wife got up and looked out and said oh there’s a man sort of waving his arms about so I thought I better get up, so you know I had to hop to the window. Of course those sort of moments you are, you notice you’re disabled. Otherwise I really feel myself very fortunate that it hasn’t really effected my life all that much”

“But I was going around here from the month of May, June, July, August, with a shell just like that, no stump in it, only a load of socks and that’s what I was walking on. So that’s what, really to be honest was putting me back an awful lot because I was afraid to go out with that. I never went outside the door for four months, four months I never went outside the door, only up here. I had to give up me job and everything. It really put me to pieces and I never, wasn’t receiving any disability allowance all the years I was here, never once, only till now. Never once”

“The helpful moment was when I was really down after the operation I had, the nurses came to talk to me, to counsel me about the situation because I was really down”.

c). Minimal limitations or impact on lifestyle

“I’m not overly concerned about mobility. Should of been. You know I keep looking at this amputee football team and disabled football and all that, water skiing that guys are doing , but I go rock climbing and stuff. So I ain’t really worried. It’s just a bit more awkward. Just have to use a bit more arm strength rather than leg strength”.

“and took up golf nine years ago, now one of the best amputee golfers in the world, got a single figure handicap and what with the new rotational ankles and everything its getting better and better for me”.

“I was always very active even before I lost my leg and it never really slowed me down very much. I don’t have a walking stick, a wheelchair, I don’t have any crutches, I haven’t been sick off work. I’ve only been sick off work three times in fifteen years as a result from my leg”.

“And we have an annual sports day where we compete in all sorts of things. Throwing the discus, javelin, archery, and you get, if you’re the winner you get a little plaque. And there’s chaps there, one of our blokes he is eighty one and he is still throwing the javelin, he had a below knee amputation , So there is no limitations to what you can do or can’t do. You got to bite the bullet that’s all”

“I wear shorts when I go on holiday, I swim. Like I say I walk round the golf course, play golf with my own bag. I think I’m one of only two amputee golfers who actually carry the bag round the golf course”

“I lead a full active life,... You know I do all the things around the house. I’m married I’ve got children and I do my gardening when I can, this sort of life. I don’t want the legs to stop me... In the old days they say well you shouldn’t be climbing over walls and that. And I say no, you make me legs to lead my life, I’m not gonna lead my life for my legs”.

“My positive drive. Life goes on . People said after my first hospital appointment, what are you gonna do now, well get up on my bike which I did at the first opportunity... It’s just personal , erh, you’re not gonna sit down, not gonna be knocked down, you will get up and do it, yeah, that sort of attitude”.

“I was given the limb and sent home and that was it , I got on with my, you know found a job and got on with my life”.

“I could do nearly everything. I mean I could play tennis I could play golf, I could go for long walks on the other hand you are disabled to a certain extent, you know. Getting up in the morning you can’t just put your clothes on in a couple of moments you have to you know it takes you a couple of minutes to put your socks on your leg on”.

Our Ref: IAS/kj/99.96.14

Dear

Re : An investigation into the psychological processes involved in adjustment to amputation - 99.96.14

Thank you for your letter 15 January 2000 which satisfactorily addresses the concerns of the Committee. I apologise for the oversight regarding the mention of tape recordings which you had quite correctly included in your original Patient Information Sheet.

I am now happy to give final ethical approval for the above named study to proceed.

With Best Wishes

Yours sincerely

**Chairman
Local Research Ethics Committee**


Please Note: All research should be conducted in accordance with the guidelines of the Ethical Committee; the reference number allocated to the project should be used in all correspondence with the Committee and the Committee should be informed:

- (a) when the project is complete.
- (b) what stage the project is at one year from today's date.
- (c) if any alterations are made to the treatment or protocol which might have affected ethical approval being granted.

- (d) all investigators whose projects have been approved by this Committee are required to report at once any adverse experience affecting subjects in the study.


DECLARATION

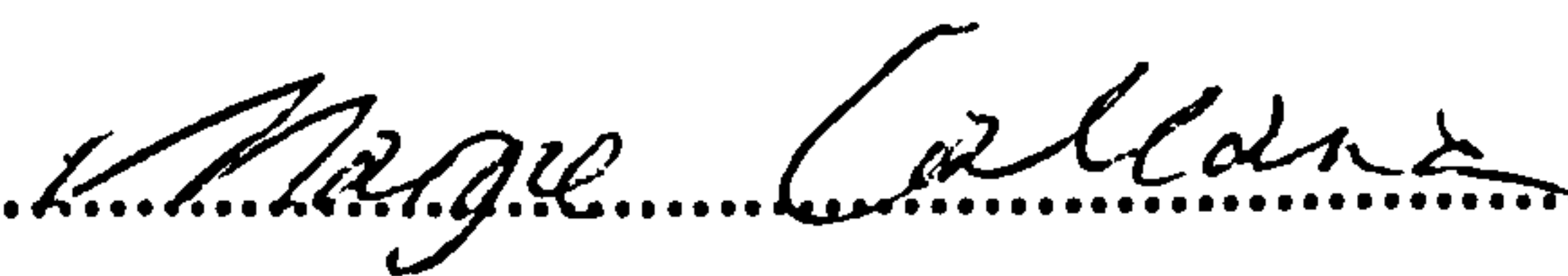
This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed ..... (Candidate)
Date 21/07/00.....

STATEMENT 1


This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed ..... (Candidate)
Date 21/07/00.....

Signed ..... (Supervisor)
Date 21/7/00.....

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed ..... (Candidate)
Date 21/07/00.....